

## INTRODUCTION

This booklet is about the decisions that must be made when breast cancer is suspected or diagnosed.

Breast cancer is the commonest cancer among women. In 1996, it caused 5300 deaths in Canada. In the same year, there were approximately 18 600 new cases.

There is considerable variation in the way in which breast cancer is diagnosed and treated across the country. Women and caregivers taking part in the National Forum on Breast Cancer held in Montreal in November 1993 identified a need for national guidelines for the care and treatment of this disease.

These guidelines, which appear here in an easy-to-read form for patients, have been prepared in response to this need. They are based on the more technical version entitled *Clinical Practice Guidelines for the Care and Treatment of Breast Cancer* that have been compiled for physicians.

Both versions contain the same basic information.

The guidelines are addressed primarily to women. However, men can also get breast cancer. Although much of the information presented is also applicable to men, some is not. Your doctor can advise you on specific differences.

### **What is a clinical practice guideline?**

A clinical practice guideline for breast cancer care is a set of recommendations to help women with breast cancer and their physicians deal with treatment issues about which there is some uncertainty. Guidelines try to resolve the uncertainty by a thorough review of all the medical evidence and extensive consultation with experts in the field.

The guidelines in this series were prepared by experts in breast cancer, representing Canadian national and provincial health agencies, and by women living with breast cancer. They reflect the best available scientific evidence and the consensus of experts across Canada.

### **A guideline is important for you, not just for your doctor**

If you know what the experts are recommending for your condition and *why* they're recommending it, then you'll know what to expect and be able to make the best personal choices. As an active participant in your own care, you'll know what's going on and you'll be able to ask the right questions. If you *don't* get the treatment you expect, you'll be in a position to find out why. If you feel uncertain at any stage, don't be afraid to get a second opinion. ♦

# Guideline 1. Investigation of a breast lump that can be felt

## **A lump can be felt in my breast. What should happen next?**

First, be aware that finding a lump is common and that most lumps are not due to cancer. However, any new lump must be investigated to find out what it is.

The investigation should start with your doctor asking about your medical history, doing a complete physical examination and usually also ordering a diagnostic mammogram. An ultrasound examination can also be valuable, especially to distinguish between cysts (harmless fluid-filled sacs) and other kinds of abnormalities.

These steps may be all that is necessary to rule out cancer, especially if your doctor is experienced in breast examination.

## **What sort of questions will my doctor ask me?**

You will be asked how long it has been since you first noticed a lump, whether it has changed at all (for example, whether it has grown bigger or changed in texture), and whether you've noticed any skin changes or irritation.

You will also be asked about possible risk factors. These are things that might increase your chance of having breast cancer at some time in your life. Your risk is higher if:

- you are older. Risk increases with age;
- you have had breast cancer before;
- you have had a breast biopsy in the past that showed some abnormality or
- you had radiation treatment for Hodgkin's disease in childhood.

Your family's health history can also contribute to your risk of getting breast cancer. The risk is higher if there is a "strong" history of breast cancer in your family. You have a strong history if the person with cancer was your mother, sis-

ter or daughter. The risk rises if more than 1 person in your immediate family had breast cancer, and if their cancer was found before menopause or before they were 50 years of age.

Although these factors are associated with an increased risk, don't be too concerned if some of them apply to you. It may reassure you to know that *most women with the common risk factors don't get cancer.*

## **What will my doctor look for during the physical examination?**

During the examination, the doctor is looking for signs that the lump is either "benign" (non-cancerous) or "malignant" (cancerous).

The armpit and the area above your collarbone will be examined to see if the lymph nodes are enlarged. These lymph nodes are sometimes called "glands." Swollen lymph nodes can be one of the first signals of a spreading cancer. The skin of the breast and the nipple will also be examined for any irritation, rash, dimpling or other abnormality that cancer can sometimes cause. Fluid leaking from the nipples unless it is blood-stained is usually not related to cancer, especially if it occurs in both breasts.

The lump itself will be felt to see if it can be moved within the tissue and whether its edges seem smooth or rough. Smooth, rounded lumps that move easily are much less likely to be cancerous. Lumps due to cancer are usually, though not always, painless.

## **What is a diagnostic mammogram? Do I need to have one?**

A diagnostic mammogram is an x-ray of the breast and is recommended when there is reason to suspect cancer. Because

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younger women (generally less than 35 years old) have denser breast tissue, mammography is less helpful in this situation.

Diagnostic mammography is more thorough than regular “screening” mammography. It includes extra compression to “push” normal breast tissue out of the way and give a clearer image of the suspicious area. If tiny flecks of calcium (microcalcifications) are noticed, magnified views will be taken since these flecks are sometimes associated with cancer.

If there is any doubt about what the mammogram shows, it is recommended that 2 individuals experienced in reading mammograms should interpret the results. For an accurate diagnosis, a high-quality mammogram is important. To ensure high quality you should check that your centre is accredited by the Canadian Association of Radiologists.

However, even when all the best procedures are followed, cancer is not always visible on a mammogram, which means that *a normal result is not absolute proof that there is no cancer.*

### **I have gone through all these steps, but my doctor still cannot rule out cancer. What is the next step?**

More tests may be necessary. Your doctor may suspect that the lump is actually a harmless cyst (a sac filled with fluid). This is a common condition. If a cyst is suspected, an ultrasound examination or a technique called “fine-needle aspiration” can help confirm the presence of a cyst.

In fine-needle aspiration, a very thin needle is inserted into the lump. If the lump is fluid-filled, the needle will draw out the fluid. If it is blood-stained it will be sent for testing. If not, you can be certain that it is only a cyst, and no further testing or treatment will be required.

### **What if the lump is solid and contains no fluid?**

If fine-needle aspiration doesn’t draw out any fluid, the lump may still be a harmless, solid fibrous growth. The needle can retrieve cells from the lump for further examination under the microscope. Sometimes, this is enough to reach a clear diagnosis.

If the answer is still unclear, further investigation will be needed. Your doctor can use a larger needle to draw out some tissue from the lump. This is then examined under the microscope to see if there are any cancer cells. This procedure is called a “core biopsy.” Your doctor may be able to locate the lump by feel; if not, a mammographic or ultrasound “picture” of the lump is used as a guide to make sure the needle goes to the right place.

If cancer is still suspected, a “surgical biopsy” is done, in which the whole lump is removed for examination under the microscope. To make sure of getting it all, some of the surrounding normal tissue is also taken.

### **What about other diagnostic techniques such as thermography, light scanning and magnetic resonance imaging (MRI)?**

Thermography, which detects the tumour’s heat, and light scanning, which shows the tumour by shining a light through the breast tissue, are inaccurate and not recommended for diagnosis.

The value of MRI is still being investigated. Right now, it is not a routine part of the diagnostic process.

### **I have a breast implant. Should I not have some of the tests?**

You can and should have the same tests (and treatments, if necessary) as

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everyone else. However, special techniques may be necessary to get a good mammographic image of a breast with an implant.

### **Will all these tests be done by my doctor?**

Reliable results depend on the skill and experience of the people who do the tests and interpret the findings. Not all doctors have the required experience and skills and not all tests are available in every location.

Depending on these factors, you may be referred to different specialists for some or all of the tests you'll need. No matter who does the investigation, the goal is to reach a reliable diagnosis using the fewest possible procedures as quickly as possible. While this goes on, you should expect to be kept fully informed. Don't hesitate to ask any questions you may have.

### **Are any more follow-up tests needed if my lump is found to have no cancer?**

It depends on the type of lump you have. For some lumps in which the diag-

nostic test results were difficult to interpret, your doctor may wish to schedule follow-up tests to be on the safe side. When the diagnosis is straightforward, however, no further tests are needed.

### **What if my lump turns out to be cancer?**

In this case, you will have more decisions to make. Together, you and your doctors will decide which kind of surgery is best for you and whether you need other treatment such as radiotherapy, chemotherapy or hormonal therapy. Guidelines 3, 4, 6, 7 and 8 in this booklet will help you with these decisions.

Above all, don't feel rushed into taking action. This is a difficult time, and it is normal to feel anxious. A delay of 1 or 2 weeks will have no significant effect on the outcome and will give you time to gather information and talk things over frankly and openly with your doctor. Don't be afraid to ask questions or to ask for any additional support you need. Family and friends can be especially important at this time. ♦

## Guideline 2. Investigation of an abnormality that is discovered by mammography

### **I had an “abnormal” result on a routine mammogram. Does this mean I have cancer?**

Most abnormalities that show up on routine mammograms are not cancer. However, more tests will be needed to make a firm diagnosis.

### **What tests will I need to have?**

Your doctor will take a clinical history, carry out a physical examination and order more thorough x-rays of the breast (a “diagnostic” mammogram). Ultrasound examination can also be valuable, especially to distinguish between cysts (harmless fluid-filled sacs) and other kinds of abnormalities.

### **What will the physical examination include?**

The doctor will thoroughly examine the breasts and the areas under the armpit and above the collarbone for signs of cancer or other conditions that could cause the abnormal image on the mammogram.

### **What if a lump is found during the physical examination?**

If a lump *can* be felt in the breast, go to guideline 1 for a description of the tests used to diagnose it, since breast lumps can be caused by several conditions. (This guideline describes the tests for abnormalities that can only be seen on the mammogram but not felt.)

### **Why do I need a another mammogram?**

You will need “diagnostic” mammog-

raphy, which is more thorough than the routine “screening” mammography you already had. Diagnostic mammography uses extra compression to “push” normal breast tissue out of the way and give a clearer image of the area where the abnormality is located. If tiny flecks of calcium (microcalcifications) are noticed, magnified views will be taken since these flecks are sometimes associated with cancer. If there is any doubt about what the image shows, it is recommended that 2 individuals experienced in reading mammograms should interpret the results. To ensure a high-quality mammogram, which is important for diagnosis, you should go to a mammography centre that has been certified by the Canadian Association of Radiologists.

### **What are the next steps?**

The next steps depend on the likelihood that cancer is present, as judged by the mammograms you have had so far.

If the abnormality is *judged to be definitely benign* (no cancer), no further investigation is needed. (You should, of course, continue to have your usual check-ups.)

Even if the abnormality cannot be diagnosed with certainty as benign, it still may be *very unlikely to be cancer*. In this situation, usually nothing is recommended except regular follow-up mammography and physical examinations to detect any suspicious change quickly. These follow-up examinations usually take place after 6, 12 and 24 months, and annually for 2 to 3 years after that if no changes are seen. If the abnormality does turn out to be cancer, it will usually

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show a change within the first year. Rarely, it may take longer.

Although this sort of abnormality is very unlikely to be cancer, there is still a very small chance that it might be. If you feel a strong need to know with certainty at this point, a biopsy can be performed.

If the *risk of cancer is judged to be intermediate* (a probability of cancer between 2% and 10%), a “needle biopsy” (either fine-needle aspiration or core biopsy) is usually recommended to remove a small amount of tissue for microscopic examination. Fine-needle aspiration removes only a few cells. A core biopsy, using a larger needle, can give a more reliable result in some instances. Since the lump can only be seen on the mammogram but not felt, the doctor will use a mammogram or ultrasound “picture” to help locate the abnormality while doing the needle biopsy.

Sometimes the *risk of cancer is judged to be high* (a probability greater than 10%). In these instances, some centres may recommend core biopsy to remove some tissue for examination, and others may recommend surgical removal of the entire area of abnormal tissue for examination. This is called a “surgical biopsy.” Just before the operation, a mammogram or ultrasound image will be used to guide the placement of tiny wires in your breast. These are needed to “mark” the abnormal area for the surgeon (since no lump can be felt). After removal the tissue is x-rayed to make sure it contains all the abnormalities seen on the mammogram. Often, if the abnormal tissue was removed during the biopsy, no further surgery is necessary.

### **I have now seen several different specialists for tests and consultations. Who can I talk to about what is happening overall?**

Usually your family doctor will coor-

dinate the investigations and give you the results. If you have been referred to a centre for breast health, the specialists there may give you the results. Make sure you know who is *your* doctor responsible for keeping *you* informed. Overall, a reliable diagnosis should be reached as quickly as possible using the fewest possible procedures, and you should understand the reasons for each test and the meaning of the results. If you feel unsure, ask.

### **What if cancer is found?**

This depends on the type of cancer that is found. One possible diagnosis is ductal carcinoma in situ (DCIS). This is a type of cancer that is located in the milk ducts. It is less likely to spread and has a better outlook than “invasive” cancers. For more information on DCIS and its treatment, see guideline 5.

If your tests show invasive cancer (cancer that has invaded the fatty tissue of the breast), you will have more decisions to make. Together, you and your doctors will decide on the kind of surgery that is best for you and whether you need to have other treatment such as radiotherapy, chemotherapy or hormonal therapy. Guidelines 6, 7 and 8 in this series will provide information to help you with these decisions.

Above all, don't feel rushed into taking action. This is a difficult time, and it's normal to feel anxious. A delay of 1 or 2 weeks will have no significant effect on your situation and will give you time to gather information and talk things over frankly and openly with your doctor. Don't be afraid to ask questions or to ask for any additional support you need. Family, friends and other women who have had breast cancer can be especially important at this time. ♦

### **Guideline 3: Mastectomy or lumpectomy? Choosing the most appropriate operation for women with early invasive breast cancer**

#### **What is mastectomy?**

*Mastectomy* is an operation that removes the whole breast. Until the mid-1980s, this was the usual treatment for early breast cancer.

#### **What is lumpectomy?**

*Lumpectomy* is an operation that removes a breast cancer growth or *tumour* along with a "shell" of normal tissue to ensure that the whole tumour is taken. Because most of the breast remains in place, lumpectomy is often called *breast-conserving surgery* (BCS). You may also hear it called *partial mastectomy* or *segmental resection*.

#### **Can I choose between mastectomy and lumpectomy?**

Yes, in most circumstances. Studies show that lumpectomy *followed by radiation therapy* — treatment with high-energy x-rays (see guideline 6)—is as effective as mastectomy. This means that both procedures can remove the tumour and reduce the chance of the cancer returning. Because the procedures are equally effective, you will need to consider your personal preferences and circumstances when choosing between mastectomy and lumpectomy. Most women with breast cancer in the early stages now choose lumpectomy with radiation therapy.

#### **What are the advantages of lumpectomy?**

Mastectomy removes the whole breast. Lumpectomy removes only a portion of the breast. Because most of the breast remains after lumpectomy, the feel and shape of the breast are usually the same as before. Plastic surgery can be used to reconstruct the breast after mastectomy, but the feel and shape may not be the same.

#### **What are the disadvantages of lumpectomy?**

There are two main issues to consider:

- *The radiation therapy required after a lumpectomy can be inconvenient and may have side effects.* You will need to have radiation therapy daily for about 4 weeks to reduce the risk of the cancer returning in the same breast. Depending on where you live, it may be difficult or even impossible to get to a treatment centre. You may also find that radiation therapy causes problems such as swelling and pain in your breast.
- *Sometimes the cancer is not completely removed during a lumpectomy.* After a lumpectomy, the tissue surrounding the tumour that was removed will be examined under a microscope. If it is found to contain cancer cells, you will need another operation — either a second lumpectomy (taking more tissue this

time) or a mastectomy. This second operation is needed because studies have shown that cancer left behind after a lumpectomy can lead to recurrence of the cancer in the breast. If only a few cancer cells are found on the edge of the removed tissue, radiation therapy may be able to destroy any remaining cells and additional surgery may not be needed.

### **If I have a lumpectomy followed by radiation therapy, can the cancer still come back in the breast?**

Yes, it can. However, the chance of this is low. About 1 in 10 women who have lumpectomy and radiation therapy will have recurrence of the cancer in the same breast after 10 to 15 years. A similar number of women who undergo mastectomy will have recurrence of the cancer in the underlying chest wall in the same time period. In some cases, chemotherapy or hormonal treatment can lower this risk. (For more information on these additional treatments, see [guidelines 7 and 8](#).) If cancer does come back in the treated breast, another operation, either lumpectomy or mastectomy, will be necessary.

### **If lumpectomy is safe and preserves the breast, what are the advantages of a mastectomy?**

Mastectomy can be preferable in certain situations:

- *If the cancer is likely to come back in the same breast, even after radiation therapy.* This can happen if there are many tumours in the breast, or if the mammogram shows that the cancer has spread to many areas of your breast. When treating cancers that are very likely to return, mastectomy can be more effective than lumpectomy.
- *If you cannot have radiation therapy.* Factors that would rule out radiation therapy include pregnancy and previous radiation treatment to the breast. Radiation therapy might also be ruled out if you have a disability or a condition such as arthritis that prevents you from lying flat or stretching out your arm, or if you have a disease such as systemic lupus erythematosus or scleroderma.
- *If the tumour is very large in proportion to the breast.* The loss of tissue when a large tumour is removed may make it impossible to preserve the shape of the breast. In this situation, a mastectomy followed by reconstruction of the breast can be more successful cosmetically than a lumpectomy.

### **Is it possible to have a lumpectomy even if I can't have radiation therapy afterward?**

Lumpectomy is still possible, but you would have a high risk of the cancer returning in the same breast (about 35% within 12 years). If the cancer does come back, you would need more surgery and perhaps treatment with anticancer drugs. Because chances are high that the cancer will return if you do not have radiation therapy, mastectomy can be more effective than lumpectomy without radiation therapy.

**My doctor says I should have the glands in my armpit removed as well. Is this usually done?**

Doctors often recommend the removal of glands or *lymph nodes* to determine how far the cancer has spread, and to reduce the risk that the cancer will come back in the armpit area. (For details, see [guidelines 4 and 13](#).)

**What if the tumour is next to the nipple?**

You can still have a lumpectomy, but the operation will require a surgeon with special skill and experience. The surgeon may need to remove some or all of the nipple and surrounding tissue. You may lose some sensation, but plastic surgery can make the shape and appearance of the breast almost normal.

**Is it possible to have a lumpectomy if my tumour is very large?**

In some situations, chemotherapy given before surgery can shrink a large tumour and thus make lumpectomy possible. In this case, though, there may be an increased risk of cancer returning in the breast after radiation therapy. You will need to discuss this possibility with your doctor when considering this option.

**What should I think about when deciding between mastectomy and lumpectomy?**

There is no evidence that one procedure is clearly superior to the other, or that one leads to a better overall quality of life. This means that your preferences, priorities and lifestyle must be your guide when making a decision. Research shows that women who take an active part in treatment decisions are less likely to feel depressed afterward. So, talk to your doctor and weigh all the information carefully. Above all, don't feel rushed when making a decision — a delay of 1 or 2 weeks will have no significant effect on your situation. You are the best judge of your feelings about your body and your response to the possible effects of either procedure. Maintaining a healthy, positive self-image over the long term is important, and you should keep this in mind when choosing between mastectomy and lumpectomy.

## Guideline 4. Removal of lymph nodes during breast cancer surgery

### What are lymph nodes?

Lymph nodes (sometimes called “glands”) are part of the system that conducts a fluid called “lymph” around the body, just as arteries and veins conduct blood. The lymph nodes that are connected to the breast area are located in the armpit and near the collarbone. When breast cancer spreads, cancer cells will usually collect in the nearby lymph nodes.

Lymph nodes are frequently removed during breast cancer surgery. Since the medical term for the armpit is “axilla,” this procedure is called “axillary dissection.”

### Why are the lymph nodes removed?

Removal of the lymph nodes for microscopic examination can give important information about how far the cancer has progressed. The recommended therapy after your surgery is different depending on whether the nodes are “positive” (contain cancer cells) or “negative” (do not contain cancer cells). Removal of lymph nodes also reduces the risk that the cancer will come back in the armpit area.

### How does the doctor know if cancer has spread to the lymph nodes?

Before your surgery, your doctor will examine your armpit and collarbone areas for any suspicious swelling. However, since cancer in the lymph nodes often cannot be felt, surgical removal and microscopic examination are needed to know for sure whether they contain cancer or not.

### Is it always necessary to remove lymph nodes?

Removal of lymph nodes is recommended as the standard procedure for women with most forms of early breast cancer. However, some types of cancer, such as ductal carcinoma in situ (DCIS), have a very low risk of spreading to the lymph nodes. (DCIS is discussed in guideline 5.) Also, in certain cases the recommended treatment is the same whether or not cancer cells are found in the nodes. In such instances it may sometimes be acceptable not to remove any nodes.

### How many lymph nodes are removed?

The lymph nodes in the armpit region are found in 3 layers, or “levels”. When breast cancer spreads, it usually goes to the level 1 nodes first, then to levels 2 and 3. It is recommended that the surgeon remove all lymph nodes found at levels 1 and 2. In general, this will result in the removal of approximately 10 lymph nodes — enough to tell for sure whether the cancer has spread to the nodes or not. Removing 10 or more nodes also reduces the chance of the cancer returning to the nodes.

However, complications become more frequent and more severe as more nodes are removed. For this reason, removal of level 3 nodes is not usually recommended.

### What kinds of complications can occur after the lymph nodes are removed?

Removal of nodes often affects nearby nerves, leading to the most common complication — numbness in the arm.

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In a few instances (less than 6%) there is also significant pain with this condition.

Another common problem is “lymphedema.” This is a pooling of lymph fluid in the arm, causing swelling, stiffness in the arm and shoulder, and sometimes infection and pain. The chance of lymphedema developing after surgery increases with the number of nodes removed. After a typical operation, between 2% and 7% of patients experience significant lymphedema. Mild lymphedema is more common and is experienced by about 1 out of every 5 patients.

Radiation treatment to the armpit area also increases the risk of lymphedema. For this reason, it should be avoided unless there is an especially high risk of the cancer coming back in this area.

#### **What can I do if I have persistent pain after my surgery?**

You do not have to live with pain, nor should you try. Guideline 10 in this series deals with chronic pain in detail, and describes recommended methods for dealing with it. ♦

## **Questions and answers on breast cancer**

### **Guideline 5. The management of ductal carcinoma in situ (DCIS) (revised Oct. 2, 2001)**

#### **What is DCIS?**

DCIS stands for “ductal carcinoma in situ” — a kind of cancer that is found only inside the milk ducts of the breast. Because the cancer has not invaded tissues outside the milk ducts, it is also called “noninvasive” breast cancer. For women who have only DCIS, the outlook is much better than for those who have invasive cancer. However, untreated DCIS may become invasive in time. It may grow through the duct wall to surrounding tissue and possibly invade other parts of the body. If this happens, the cancer is no longer DCIS and must be treated as invasive cancer. The treatment described in this guide is for women who have *only* DCIS, not invasive breast cancer.

#### **How common is DCIS?**

Since more women in Canada are now having screening mammograms, DCIS is being diagnosed more frequently. DCIS now accounts for between 20% and 25% of all breast cancers detected in women who have regular mammograms.

#### **What if DCIS and invasive breast cancer are found together?**

Because almost all breast cancers start inside the milk ducts, almost every laboratory report for breast cancer will describe some DCIS. When DCIS and invasive cancer are found at the same time, treatment for invasive cancer will be needed.

#### **How will I know if I have DCIS?**

There are usually no warning signs, such as a lump in the breast, when a woman has DCIS. Most often, evidence of DCIS shows up on a mammogram taken at a screening clinic. Your doctor may suspect that you have DCIS if “calcifications” (deposits of calcium) can be seen on your mammogram. However, you will only know for sure that you have DCIS if a piece of breast tissue is removed and examined in a procedure called a “biopsy.” A common kind of biopsy is a “needle” biopsy, where a small tissue sample is removed using a needle. The sample is then examined under a microscope by a

pathologist (a doctor specializing in the examination of tissue). If the pathologist sees typical cancer cells inside the milk ducts, then a diagnosis of DCIS is made.

### **Why has my doctor recommended a surgical biopsy?**

If your first biopsy was a needle biopsy that contained cancer cells, you will need a “surgical” biopsy to find out if the cancer has invaded any of the surrounding tissue. For this kind of biopsy, a larger amount of breast tissue is removed. (If DCIS seems very likely, a doctor will often recommend that a surgical biopsy rather than a needle biopsy be done first.) A surgical biopsy is crucial, since any cancer that spreads outside the milk ducts is invasive cancer rather than simply DCIS and will need a different kind of treatment.

When a surgical biopsy is done, the abnormal tissue is removed in one piece and x-rayed. Samples of the tissue are then examined under a microscope. If an x-ray of the removed tissue suggests that all of the cancer was *not* removed completely, you will need a second mammogram after your breast tissue has had a chance to heal. You may also then need another operation to remove cancer cells left behind.

### **My surgical biopsy shows that I have DCIS. What should I do next?**

When you have been fully informed of the findings from your surgical biopsy, you can begin to consider your treatment choices. DCIS is not a fast-growing cancer, so it is quite safe to take the time you need to consult with your doctors, family members, friends and other women who have had breast cancer.

### **What is the best treatment for me?**

The first thing to consider is the possibility that the surgical biopsy did not remove all of the cancer. If there is a chance that some cancer cells were left behind, more treatment is required. This usually means more surgery. Your chief task will be to decide which type of surgery is best for you.

In the past, a diagnosis of DCIS always meant “mastectomy” (removal of the whole breast), and this may still be the best option for some women. The other option is “lumpectomy” (also known as “breast-conserving surgery”) followed by radiation

treatment (“radiotherapy”). Lumpectomy followed by radiotherapy is now the generally recommended treatment for early invasive breast cancer, and is also used for DCIS.

Whether you choose mastectomy, or lumpectomy followed by radiotherapy, survival rates are very high: between 95% and 100% for women 10 years after surgery.

If the surgical biopsy removes all of the cancer and no other suspicious areas for cancer are found in the breast, then the surgical biopsy can be considered as a lumpectomy and no further surgery is required.

### **What factors should I consider when choosing between mastectomy and lumpectomy?**

You will need to talk to your doctor about the type of DCIS that was found in your breast, and how much of the breast is involved. You will also want to consider the factors listed below, many of which are discussed in more detail in [guideline 3](#).

- *Your concerns about appearance.* The first thing you must consider is whether you want to save the breast. This is a very personal and individual matter. Some women want to maintain the original appearance of their breasts if at all possible. For these women, a lumpectomy that removes the cancer and leaves enough tissue to make the breast look and feel natural is most desirable. Other women want to do whatever they can to lower the chance of recurrence. These women can choose a mastectomy. Women who choose mastectomy can consider breast reconstruction to make it easier to live with the body changes and still feel confident that the cancer will not return. Because the chances of controlling the cancer are excellent either with mastectomy or with lumpectomy and radiotherapy, many women today choose to save the breast. You will need to pick the surgical option that makes you feel best.
- *The presence of cancer cells at the cut edges of tissue removed during the surgical biopsy.* When examination of the tissue removed during the surgical biopsy shows that there are cancer cells at the cut edges, a women choosing lumpectomy may need a second or even third operation to remove more tissue. If you want to avoid the possibility of several operations, you may want to consider mastectomy.
- *The likelihood that the cancer will come back in the same breast.* If your tumour is large or has other features that suggest that recurrence of the cancer is likely (e.g.,

cancer cells are found close to the cut edges of the removed tissue or it is an aggressive type of cancer), you may want to consider mastectomy.

- *The amount of tissue to be removed.* When there is more than 1 tumour or when the tumour is large, a lumpectomy will require the removal of a great deal of tissue. If the lumpectomy will leave the breast disfigured, you may want to consider mastectomy, or mastectomy followed by reconstruction of the breast.
- *Your ability to undergo radiotherapy.* Radiotherapy is usually recommended after lumpectomy because it reduces the risk of the cancer coming back in the same breast. If you cannot have radiotherapy for any reason, or if it will be very difficult or inconvenient for you to do so because of your job or your distance from a treatment centre, you may want to consider mastectomy. (In a small number of cases, if the tumour is quite small *and* has no features indicating that it is especially likely to return, *and* if it is certain that all the diseased tissue was removed, lumpectomy *without* radiotherapy may be considered. You should, however, consider this option only after fully exploring the issues with your doctor.)
- *The possible complications related to each procedure.* All treatments carry the possibility of unwanted side effects. Persistent pain, swelling and delayed healing of the wound can occur with either lumpectomy or mastectomy, but they are more common with mastectomy. The radiotherapy that follows lumpectomy can also cause unwanted side effects, including fatigue, pain, tenderness and scarring of the breast. For more details about radiotherapy, see [guideline 6](#).

### **Should the lymph nodes in the armpit also be removed?**

Lymph nodes (sometimes called “glands”) are frequently removed for invasive breast cancer, but not for DCIS. This is because it is very rare for cancer to spread to the lymph nodes in DCIS, and any benefit of removal of the lymph nodes is outweighed by the possible complications of the operation.

### **If I have a mastectomy for DCIS, can the skin and nipple be kept intact for plastic surgery later?**

This procedure (called “subcutaneous mastectomy”) has been done for patients with DCIS in the past because it gives a good cosmetic result. However, because it leaves 10% to 15% of the breast tissue behind, it only partly removes the risk of the cancer returning and is not as safe as mastectomy. If you are choosing mastectomy to minimize the risk that the cancer will recur, subcutaneous mastectomy is not recommended.

**What about other treatments, such as tamoxifen?**

There is some scientific evidence that treatment with tamoxifen, a drug that can prevent growth of cancer cells, may benefit women with DCIS who have had lumpectomy. You and your doctor will need to discuss whether the benefit of using tamoxifen outweighs any side effects (see [guideline 12](#)).

## Appendix 1

### Questions and answers on radiation therapy after lumpectomy

#### A guide for women and their physicians

#### **What is a lumpectomy?**

A *lumpectomy* is an operation that removes a breast cancer growth or *tumour* along with a “shell” of normal tissue to ensure that the whole tumour is taken. Because most of the breast remains in place, lumpectomy is often called *breast-conserving surgery (BCS)*. Until a few years ago, women with breast cancer almost always had a *mastectomy* — an operation to remove the whole breast. Lumpectomy is a less radical operation that removes only the diseased part of the breast and leaves healthy breast tissue in place. Studies have shown that women who have a lumpectomy followed by radiation treatment live just as long as women who have a mastectomy (see [patient guide to guideline 3](#)). Four out of 5 women with breast cancer have tumours that can be treated by lumpectomy.

#### **What is radiation therapy?**

*Radiation therapy* (also called *radiotherapy*) is the use of high-energy x-rays to kill cancer cells.

#### **Will I need radiation therapy if I have a lumpectomy?**

Yes, radiation therapy is almost always recommended after lumpectomy. Cancer can return in the same breast after surgery (*local recurrence*). Studies have shown that radiation therapy significantly reduces the risk of local recurrence. Although there are no guarantees, the benefits of radiation therapy are so great that you should definitely consider it as part of your treatment. Keep in mind that more than 90% of women are satisfied with the appearance of the breast after lumpectomy and radiation treatment.

#### **My doctor says my cancer is not likely to return because I am over 50 years old and my tumour was very small. Should I still consider radiation therapy?**

Although it is true that your risk of recurrence is relatively low, about 1 in 10 women over age 50 with small tumours will have a recurrence of cancer within 8 years if they have a lumpectomy *without* radiation therapy. Radiation therapy can reduce this risk to about 1 in 50 women and provide an extra margin of safety. Some women with early breast cancer will take tamoxifen after surgery (see [patient guides to guidelines 7 and 8](#)). Radiation therapy can help these women as well, and they should not avoid radiation therapy just because they are taking tamoxifen.

#### **Does radiation therapy have unpleasant or dangerous side effects?**

Radiation therapy can have side effects that occur both during and after the treatment. In the first weeks after radiation therapy starts, you may notice the skin in the breast area reddening or swelling and you may feel very tired. These problems usually disappear within 3 to 6 months. In the first 5 years after treatment, you may experience discomfort, pain, swelling, discolouration or other skin changes in the breast area. As well, some breast tissue may shrink or become hard when fat cells die, especially in areas that receive high-dose treatments. This hardening does not mean that the cancer has come back.

With current radiation therapy techniques, severe long-term side effects are rare. Even in the past, when radiation therapy involved different techniques and higher doses of radiation than would be recommended today, serious problems occurred in less than 1% of patients treated.

### **Can the radiation cause cancer?**

Any danger from radiation depends on the type of radiation, the amount given and the way it is applied. There is no convincing evidence that the kind of radiation therapy given after lumpectomy can cause cancer, either in the breast or elsewhere in the body.

### **Tissue was removed from one small area of my breast, but my doctor wants to treat the whole breast with radiation. Is this a good idea?**

There is clear evidence that radiation treatment of the whole breast prevents recurrence more effectively than radiation treatment of part of the breast.

### **What is a boost?**

A *boost* is an extra dose of radiation given directly to the small area where the cancer was removed. Most often it is used when the tissue removed is examined under a microscope and cancer cells are found in the area surrounding the tumour. This indicates that all cancer cells were probably not taken out during the lumpectomy. Normally, a second operation to remove the remaining cancer is the best choice. However, if this is not possible for some reason, or if you decide against having more surgery, a boost of radiation to the area can be the “next-best” option. Recent research indicates that boost irradiation can reduce the risk of local recurrence of breast cancer, but it can also lead to poorer cosmetic results than would be achieved with no boost. Your doctor may ask you to consider a boost following breast radiation therapy when there is a high risk of local recurrence (for example, if you are less than 40 years of age or if cancer cells were found in the tissue bordering your tumour).

### **How is radiation therapy given?**

Radiation therapy is not given all at once. It is divided into *fractions* — small doses — and is usually given 5 days a week for 3 to 6 weeks. If boosts are given, they are also divided into fractions.

### **Is there a “best” treatment schedule or a “right” dose of radiation?**

A number of treatment schedules have been used, and study results suggest that they all produce similar benefits. Because all of these schedules are acceptable, it may be possible to choose the treatment program that best suits your timetable. However, it is important to stay within a standard range. Unusually high doses of radiation can cause more severe side effects without providing any extra benefit. Results of a recent Canadian study have shown that a schedule of treatments given over 22 days is as good as one given over 35 days.

### **When should radiation therapy begin?**

- *If you are not having chemotherapy (treatment with anticancer drugs):* Radiation treatment should begin as soon as possible after your lumpectomy incision heals, usually within 8 weeks after surgery. It is generally believed that radiation therapy should not be delayed longer than 12 weeks after surgery, although there is no proof to support this.

- *If you are having chemotherapy:* Radiation treatment should be delayed until your chemotherapy is finished. Sometimes both kinds of treatment are given together. However, there is no evidence that this combination treatment improves the outcome, and it can increase the risk of unwanted side effects, especially if Adriamycin or other anthracycline-containing drugs are used as part of your chemotherapy.

**Should some women *not* receive radiation therapy after lumpectomy?**

Women who are pregnant or who have had previous high-dose radiation therapy to the chest (including radiation therapy for Hodgkin's disease) should definitely not receive radiation therapy.

Women with heart or lung disease, systemic lupus erythematosus or scleroderma should probably not have radiation therapy because of their increased risk of severe side effects from radiation treatments. Women with arthritis and other conditions that make it hard to lie flat or to stretch out the arm on the same side as the breast being treated may find it difficult or impossible to receive radiation treatments.

## Questions and answers on breast cancer

### Guideline 7: Anticancer drug treatment for node-negative breast cancer

#### What is node-negative breast cancer?

Node-negative breast cancer means that no cancer cells from the breast have been found in the lymph nodes (sometimes called “glands”) in the armpit area. If your cancer is node negative, there is a lower risk of the cancer returning and spreading than if it is node positive.

#### I will be having surgery and radiation treatment for breast cancer. Do I need anticancer drug treatment too?

Although node-negative cancer indicates a smaller risk of the cancer returning than node-positive cancer, there is still a risk. Even when it seems certain that the whole tumour has been removed, cancer still returns elsewhere in the body (“metastasizes”) in up to 30% of all women with node-negative breast cancer.

However, this is simply an average. Some kinds of cancer are more likely to recur than others, and this will influence your treatment options. Your cancer will be examined and classified as having a *high*, *medium* or *low* risk of returning, depending on several factors outlined below.

- *Its size.* The larger the cancer, the higher the risk. Most cancers smaller than 1 cm in diameter are at a very low risk of recurring after surgery and radiation.
- *The type of cells it contains.* Some cell features are found more often in “aggressive” cancers, cancers that are more likely to recur and spread. Your pathologist will “grade” your cancer from I to III depending on its cell features. A grade I cancer is less likely to return than a grade III cancer.
- *Whether the cancerous cells have invaded nearby blood vessels and lymph channels.* When vessel invasion is found under the microscope, the cancer is more likely to return.
- *Whether your cancer was diagnosed as “ER positive” or “ER negative.”* “ER” stands for estrogen receptor. This is a receptor or “docking site” to which estrogen can bind. Women with cancers that have these receptors (ER-positive cancers) are at a slightly lower risk of the cancer returning. Also, such cancers react differently to treatment than ER-negative cancers.

All these factors must be considered when judging your overall risk of the cancer returning. This, in turn, will determine whether you should have additional treatment and, if so, which treatment is best for you.

**What is the risk that the cancer will return if I have only surgery and radiotherapy, but no additional drug treatment?**

If your cancer is classified as *low risk*, there is less than a 10% chance it will return in the next 10 years. In other words, it will come back in fewer than 10 women out of every 100 who have this type of cancer.

If cancer is classified as *intermediate* risk, the chance of the cancer returning is somewhere between 10% and 20%. Additional treatment will reduce this risk.

Women with *high-risk* cancers have a greater than 20% risk of the cancer returning and spreading. This risk is sometimes as high as node-positive breast cancer. For this group also, additional treatment will reduce this risk.

**My cancer has been classified as *low risk*. Do I need additional treatment?**

No. In your case, additional drug treatment is not recommended, since only 1 or 2 out of every 100 women would benefit from it. Your doctor may discuss the use of hormonal therapy with tamoxifen.

**My cancer is classified as *high risk*. What additional treatment is recommended for me?**

Chemotherapy is recommended for all premenopausal women and for postmenopausal women with ER-negative tumours.

Tamoxifen plus chemotherapy is recommended for postmenopausal women with ER-positive tumours. The increased toxicity of chemotherapy must be considered.

These treatments are discussed in more detail below.

**What is recommended for women with *intermediate-risk* cancer?**

If the cancer is ER positive, hormonal therapy with tamoxifen is recommended. This treatment is discussed in more detail below. (ER-negative cancers are usually classified as high risk.)

Chemotherapy provides additional benefit to tamoxifen. However, the magnitude of the benefit is small, and the increased toxicity of chemotherapy must be considered.

## **Chemotherapy**

### ***What is chemotherapy?***

Chemotherapy is treatment with drugs that kill cancer cells.

### ***My doctor recommends chemotherapy. What are the pros and cons?***

Anticancer drugs also affect healthy cells. This means they can have undesirable side effects, some of which are severe. For this reason, chemotherapy is recommended only when there is a good chance that you will benefit from it and are healthy enough to take it.

For premenopausal women and for women with ER-negative cancers, chemotherapy is the most effective means available for guarding against a return of the cancer. Since it can prolong your life, it would be unwise to refuse it without good reason. As described below, there is some room for choice between drug combinations in terms of specific side effects and length of treatment.

### ***How is chemotherapy given?***

There are two recommended combinations of drugs for treating women with node-negative breast cancer: CMF and AC. Both have proved effective.

The combination you choose is given in “cycles” as shown below.

- CMF (cyclophosphamide, methotrexate and 5-fluorouracil)

With this choice, you would take cyclophosphamide by mouth every day for 2 weeks. On the first day of each of these weeks you would also receive methotrexate and 5-fluorouracil by intravenous injection. Then there is a 2-week “rest period” when no drugs are given. This completes 1 full cycle. Six cycles are given altogether, for a total of 6 months of treatment.

- AC (Adriamycin [doxorubicin] and cyclophosphamide)

With this combination you do not have to take daily medication. Instead, you would receive the drugs by intravenous injection and then have a rest period of 21 days (3 weeks) when no drugs are given. On the 22nd day you would begin the second cycle. Four cycles are given altogether. The whole treatment lasts a little over 2 months.

### ***What are the most common side effects of chemotherapy?***

Side effects can include the following:

- Nausea and vomiting. If you are being treated with the CMF combination, nausea and vomiting will be mild to moderate and will last throughout treatment. However, it can be effectively relieved with medication. If you choose the AC combination, nausea and vomiting are likely to be more severe, but will be much briefer.
- Fatigue is common.
- Some weight gain may occur in about 14% of patients.
- Temporary hair loss. Hair loss is complete with AC. With CMF, 30% of patients have no hair loss at all, and only 40% have severe hair loss.
- Mild irritation of the eyes, the lining of the mouth and throat, and inflammation of the bladder.
- Temporary stoppage of monthly periods during treatment. In older women this may become permanent.
- Temporary suppression of the body's immune system during treatment. This increases the risk of infection. In a few individuals (2%), it may cause fever, requiring hospitalization.
- Severe side effects are rare, occurring in less than 1% of women receiving the usual doses of chemotherapy. However, they do happen, and chemotherapy can very rarely even be fatal. There is a very small risk of heart damage with AC. There is also a very small risk of leukemia developing in later life (perhaps 1 in every 1000 to 10 000 patients).

### ***When should chemotherapy begin?***

Chemotherapy should begin as soon as possible after your operation, usually within 8 weeks.

### ***If I take chemotherapy, do I need any other treatment?***

If you have a lumpectomy, radiotherapy will also be recommended. If you are having chemotherapy, the radiotherapy is usually delayed until the chemotherapy is finished. For more information on radiotherapy, see guideline 6 in this series.

## **Hormonal therapy**

### ***My doctor has recommended hormonal therapy. What does this mean?***

The ovaries produce hormones such as estrogens, which can encourage the growth of breast cancers, especially those that are ER positive. Hormonal therapy with the drug “tamoxifen” interferes with this process without stopping the body's hormone production.

Tamoxifen has been found to prolong life in women with breast cancer, and it also reduces the chances of getting cancer in the opposite breast.

### ***For how long should tamoxifen be taken?***

It is recommended that you take the standard dose of tamoxifen (20 mg) by mouth every day for 5 years.

### ***What are the side effects of tamoxifen?***

Tamoxifen can cause temporary hot flashes in up to 20% of patients. Blood clots in the veins will develop in about 1 in every 100 patients taking tamoxifen. Rarely, these may pass into the lung, endangering life. Very rarely (about 1 woman in every 500 treated), tamoxifen can cause cancer in the lining of the uterus (endometrial cancer). For this reason, women taking tamoxifen should promptly report any vaginal bleeding — even slight spotting. Very rarely tamoxifen can cause cataracts.

Tamoxifen lowers the chance of cancer in the opposite breast and reduces the risk of osteoporosis — a common cause of “brittle bones” and fractures in postmenopausal women.

## **What is node-positive breast cancer?**

Node-positive breast cancer means that cancer cells from the tumour in the breast have been found in the lymph nodes (sometimes called “glands”) in the armpit area.

Although the breast cancer is removed during surgery, the presence of cancer cells in the lymph nodes means that there is a higher chance of the cancer returning and spreading.

## **I will be having surgery and radiation treatment for breast cancer. Do I need drug treatment too?**

Almost all women with node-positive breast cancer require drug treatment in addition to surgery and radiation treatment (radiation is given following lumpectomy). Even when it seems certain that the whole tumour has been removed, many women die within 10 years from the cancer returning if they have had only surgery and radiation without drug treatment. There is now very powerful evidence that drug treatment in addition to surgery and radiation helps prolong life.

## **What does “drug treatment” mean?**

Drug treatment can mean either chemotherapy or hormonal therapy. Chemotherapy uses special drugs to kill cancer cells.

Hormonal therapy uses a different approach. The ovaries produce natural hormones, such as estrogen, which encourages some cancers to grow. Hormonal therapy interferes with this process and can stop or slow the growth of cancer cells.

There are 2 kinds of hormonal therapy. The first, called “ovarian ablation,” stops hormone production by destroying the ovaries with radiation treatment or by removing them surgically. In the second type of hormonal therapy, estrogen is still produced by the body, but its effect is blocked by a drug called “tamoxifen.”

The recommended treatment depends on individual circumstances.

## **What kind of therapy is best for me?**

Several factors have to be considered. These include the following:

- *Your age, and whether you have gone through menopause (“change of life”).* Medication affects cancers differently before and after menopause.
- *Whether your cancer was diagnosed as “ER positive” or “ER negative.”* “ER” stands for estrogen receptor. This is a receptor or “docking site” to which estrogen can bind. If a tumour has these receptors (ER-positive cancer), it means that its growth may be influenced by your body’s natural hormones. This will affect the type of treatment recommended for you.
- *Your personal choice.* For example, one treatment may be slightly more effective than another but has more unpleasant side effects, which may affect your choice. You and your doctor will need to weigh the expected benefits against the possible problems that the treatments can cause.

Each of the treatments mentioned in the following columns are discussed in more detail later. The first choices to be made depend on your age and whether you have passed menopause. Menopause occurs over a period of time. You should consider yourself postmenopausal when you have not had your period for a year. Until then, for the purposes of cancer treatments, you are considered premenopausal. Women who can't tell (they may have had their uterus removed) are considered to be postmenopausal after their 50th birthday.

**Read this column if you are premenopausal**

There is strong evidence that chemotherapy using a combination of drugs can prolong life and is the best choice for you.

***Should I have hormonal therapy in addition to chemotherapy?***

Right now, there is not enough evidence to recommend taking both.

***Can I have hormonal therapy instead of chemotherapy?***

A decision to refuse chemotherapy should not be made lightly. Hormonal therapy is less effective than chemotherapy for your situation.

However, if you are unable or definitely unwilling to have chemotherapy and your cancer was ER positive, hormonal treatment (ovarian ablation or tamoxifen) can have some benefit by itself.

***If I have chemotherapy, what drugs will I be taking?***

Three combinations have been widely tested and have proved effective. They are known as CMF, AC and CEF. Research studies are investigating adding a new class of drug called taxanes to AC chemotherapy, but the results are inconclusive. The best choice for you depends on your personal circumstances. Each combination is discussed in detail further on.

***If I have hormonal therapy, what kind will it be?***

If you can't have chemotherapy, ovarian ablation (surgical removal or radiation-induced destruction of the ovaries) may be the best choice for you. Although it is seldom used in Canada at present, ovarian ablation has proved effective in cases like yours. If you are unable or unwilling to have ovarian ablation and your cancer was ER positive, tamoxifen can be used.

For more information, read the sections on Chemotherapy and Hormonal Therapy (including ovarian ablation) that follow.

**Read this column if you are postmenopausal**

The best treatment for you depends on whether your cancer was ER negative or ER positive.

***My cancer was ER negative. What is the best treatment for me?***

If you are in good general health, chemotherapy is the best choice for you. Hormonal therapy is not recommended.

***What is the best therapy if my cancer was ER positive?***

If your cancer was ER positive, hormonal therapy is recommended. Chemotherapy can provide additional benefit to hormonal therapy.

***If I take chemotherapy, what drugs will I be taking?***

Two combinations have been widely tested and have proved effective in cases such as yours. They are known as CMF and AC. The best choice for you depends on your own personal circumstances. Each combination is discussed in detail further on.

***If I have hormonal therapy, what kind will it be?***

Treatment with tamoxifen is the recommended hormonal therapy for you.

***If my doctor recommends tamoxifen, do I also need chemotherapy?***

Chemotherapy can provide additional benefit to tamoxifen. If this possibility is important to you and you are willing to accept the unpleasant side effects of chemotherapy, this may be an option for you.

For more information, read the sections on Chemotherapy and Hormonal Therapy (tamoxifen) that follow.

## Chemotherapy

### *My doctor recommends chemotherapy. What are the pros and cons?*

Anticancer drugs also affect healthy cells. This means they can have undesirable side effects, some of which are severe. For this reason, chemotherapy is recommended only when you are strong enough to take it.

For premenopausal women and for women with ER-negative cancers, chemotherapy is the most effective means available for guarding against a return of the cancer. Since chemotherapy can prolong your life, it would be unwise to refuse it without good reason. As described below, there is some room for choice between drug combinations in terms of specific side effects and length of treatment.

### *How is chemotherapy given?*

There are 3 recommended combinations: CMF, AC and CEF. Premenopausal women can take any of them. Postmenopausal women can take either CMF or AC. All of them have proved effective against cancer. Research studies are investigating adding a new class of drug called taxanes (e.g., paclitaxel) to AC chemotherapy. The results are inconclusive. You can discuss this option with your doctor.

The combination you choose is given in “cycles” as shown below.

- **CMF (cyclophosphamide, methotrexate and 5-fluorouracil)**  
With this choice, you would take cyclophosphamide by mouth every day for 2 weeks. On the first day of each of these weeks you would receive methotrexate and 5-fluorouracil by intravenous injection. Then there is a 2-week “rest period” when no drugs are given. This completes 1 full cycle. Six cycles are given altogether, for a total of 6 months of treatment.
- **AC (Adriamycin [doxorubicin] and cyclophosphamide)**  
With this combination you do not have to take daily medication. Instead, you would receive the drugs by intravenous injection and then have a rest period of 21 days (3 weeks) when no drugs are given. On the 22nd day, you would begin the second cycle. Four cycles are given altogether. The whole treatment lasts a little over 2 months.
- **CEF (cyclophosphamide, epirubicin and 5-fluorouracil)**  
This combination is given in the same way as CMF. The cyclophosphamide is taken by mouth every day for 2 weeks, and an intravenous injection of the other 2 drugs is given on the first day of each of those weeks. This is followed by a 2-week rest period, which completes the cycle. Six cycles are given altogether for a total of 6 months of treatment. Usually, when CEF is used, it is recommended that you take an antibiotic to guard against infection.
- **AC followed by paclitaxel**  
AC is administered as described above. Three weeks after the last cycle of AC, paclitaxel is given by intravenous injection. Four doses of paclitaxel are given, one dose every 3 weeks.

### ***What are the most common side effects of chemotherapy?***

Side effects can include the following:

- If you are being treated with CMF chemotherapy, nausea and vomiting can be mild to moderate and can last throughout treatment. However, they can be effectively relieved with medication. If you choose AC chemotherapy, nausea and vomiting are likely to be more severe than with CMF, but they will be much briefer in duration. If you are being treated with CEF chemotherapy, nausea and vomiting can be moderate. However, they can be effectively relieved with medication.
- Fatigue is common.
- Some weight gain may occur in about 14% of patients.
- Hair loss is complete with AC and CEF, but your hair will grow back after completion of chemotherapy. With CMF, 30% of patients have no hair loss at all, and only 40% have severe hair loss.
- Mild irritation of the eyes and the lining of the mouth and throat, and inflammation of the bladder may occur.
- Temporary stoppage of monthly periods during treatment may occur. This side effect may become permanent in older women.
- Temporary suppression of the body's immune system may occur during treatment and can increase the risk of infection. In a few individuals (about 2% to 5%), it may cause fever, necessitating admission to hospital.
- Severe side effects are rare, occurring in less than 1% of women receiving the usual doses of chemotherapy. However, they can happen, and chemotherapy can very rarely even be fatal. There is a very small risk of heart damage with AC (less than 1%) and a small risk of heart damage with CEF (1%). There is also a very small risk of leukemia developing in later life with AC or CMF (perhaps 1 in every 1000 to 10 000 patients) and a small risk with CEF (1%).

### ***When should chemotherapy begin?***

Chemotherapy should begin as soon as possible after your operation, usually within 4 to 6 weeks.

### ***If I take chemotherapy, do I need any other treatment?***

If you have had a lumpectomy, you should also have radiotherapy. If you are having chemotherapy, the radiotherapy is usually delayed until the chemotherapy is finished. For more information on radiotherapy, see guideline 6 in this series.

## **Hormonal therapy**

### ***My doctor has recommended hormonal therapy. What does this mean?***

The ovaries produce hormones such as estrogen, which can encourage the growth of breast

cancer. There are 2 kinds of hormonal therapy: ovarian ablation, which stops the body's hormone production, and the drug tamoxifen, which blocks the action of the body's hormones.

### ***What is ovarian ablation?***

Ovarian ablation stops the production of hormones in the ovaries, in effect causing menopause in premenopausal women. This is done by removing the ovaries through surgery or by destroying them with radiation treatment. The effects are permanent.

### ***What are the side effects of ovarian ablation?***

Ovarian ablation produces all of the usual symptoms of menopause, including hot flashes and mood swings. However, these symptoms are temporary. There is also a small increased risk of heart disease and osteoporosis (brittle bones), as happens in all women after menopause.

### ***How does tamoxifen work?***

Hormones such as estrogens that are produced in the ovaries can make cancers grow faster, especially those that have estrogen receptors (ER-positive cancers). Tamoxifen does not stop hormone production but blocks the hormones from reaching the cancer cells. The drug is taken daily by mouth.

Tamoxifen has proved to be effective in prolonging life in women who have been treated for breast cancer. It also reduces the chances of getting cancer in the opposite breast.

### ***For how long should tamoxifen be taken?***

It is recommended that tamoxifen treatment be continued for 5 years.

### ***What are the side effects of tamoxifen?***

Tamoxifen may cause temporary hot flashes in up to 20% of patients. In about 1 in every 100 patients, treatment with tamoxifen may cause blood clots in the veins. Rarely, these can pass into the lung, endangering life. Very rarely (about 1 woman in every 1000 treated) tamoxifen can cause cancer in the lining of the uterus (endometrial cancer). For this reason, women taking tamoxifen should promptly report any vaginal bleeding — even slight spotting. Very rarely tamoxifen can cause cataracts.

Tamoxifen has some beneficial side effects, too. It lowers the chance of cancer in the opposite breast and reduces the risk of osteoporosis — a common cause of brittle bones and fractures in postmenopausal women.

# Questions and answers on follow-up care after breast cancer treatment

## A guide for women and their physicians

### **My treatment for breast cancer is almost finished. Will I need further medical care?**

Yes. Everyone who has been treated for breast cancer should continue to visit the doctor regularly for the following reasons:

- *To receive ongoing support.* Regular visits will allow you to discuss problems and deal with any side effects of treatment. Regular visits will also help you find emotional or social support if you need it. At your first visit after treatment you can work out a schedule with your treatment team for long-term care.
- *To detect any problems — especially recurring or new cancer — as soon as possible.* Cancer can recur in the breast following treatment, or a new cancer can start in your other breast. Regular physical and radiological examinations (*mammography*) can help find any recurring or new cancer in the breast at an early stage.

### **Who will be responsible for my follow-up care?**

You will usually begin by seeing the specialist who has supervised your treatment: the surgeon, the medical oncologist or the radiation oncologist. If several specialists have been involved, some or all of them may wish to see you at first. Later, with your participation and agreement, one of the specialists or your family doctor may become responsible for coordinating your care. No matter who is coordinating your care, all of the members of your treatment team should keep you fully informed and let you know exactly what follow-up arrangements have been made and who is responsible for carrying them out.

### **How often should I visit the doctor?**

No single schedule has been found to suit everyone. The timing of visits should be set to suit your individual needs. In general, follow-up visits should be scheduled every 3 to 6 months during the first 3 years after treatment. During the following 2 years, visits should be scheduled every 6 to 12 months. Once 5 years have passed since your treatment, you should visit your doctor once a year. It is recommended that these yearly visits continue for life.

### **What will happen on my follow-up visits?**

Every visit should include an updating of your medical history and a physical examination. Yearly visits should also include mammography.

- *Medical history.* Your doctor will want to know about any side effects of treatment, such as swelling or tenderness in your breasts, stiffness in your shoulder or swelling in your arm, since your last visit. If you are taking tamoxifen as part of your treatment and haven't had your uterus removed (*hysterectomy*), you should tell your doctor about any vaginal bleeding — even slight spotting. This is because the risk of cancer in the lining of the uterus (*endometrial cancer*) is slightly higher for women taking tamoxifen.
- *Physical examination.* The main purpose of this examination is to look for recurrence of cancer and for new cancers in the other breast. The doctor will examine your

breasts, your chest wall and abdomen, and the lymph nodes in your armpit and collarbone areas. The doctor will also examine your arm for *lymphedema* (swelling caused by a buildup of lymphatic fluid), something that can occur after lymph nodes are removed from the armpit.

**Should I have regular tests to make sure the cancer hasn't come back somewhere else?**

No. The only regular test you need is a mammogram. A yearly mammogram is recommended to detect any recurrence of cancer in the treated breast and any new cancer in the other breast. The chance of a cure is better when a new breast cancer is found early.

If cancer does spread to other parts of the body, life expectancy is the same whether the cancer is detected early or not. Because little is gained from the routine use of other tests — for example, bone and liver scans, chest x-rays, blood tests, tests for tumour markers — such testing is generally not recommended.

**What if I feel something is wrong between regular visits?**

After treatment for breast cancer, many women will experience pain or other unpleasant symptoms. If these problems come and go, or disappear within a week or so, they are very unlikely to be related to cancer. But sometimes a problem does not go away. If you have new symptoms that continue to bother you, do not wait for your next regular appointment. Call your doctor if you have any of the following:

- new pain that won't go away
- a cough that won't go away
- a lump in either breast
- unusual changes at the site of your surgery or in the scar itself
- a tired feeling that won't go away
- loss of appetite
- tingling or numbness in the arm or hand
- swelling of the arm (even slight swelling can mean you have lymphedema, which is easier to treat if recognized early)
- any new symptom that is unusual or severe and doesn't go away

**I feel that I am having difficulty thinking and remembering. Is this because of the treatment?**

Some studies suggest that chemotherapy can affect your ability to think and remember. However, the studies done so far have not clearly established that this is the case. Nor have the studies determined if the change is a long-lasting one. Other factors related to your treatment — tiredness, emotional distress — can also affect thinking and remembering.

**I feel very tired. Is there anything I can do?**

Feeling tired is very common during treatment for breast cancer. After treatment is finished, you should feel less tired. If you do not notice any improvement over the course of several months, talk to your doctor.

**I have put on weight during my treatment. Should I now try to lose weight?**

Weight gain is common, particularly for women receiving chemotherapy. It is uncommon for women using tamoxifen. Although some studies suggest a relation between obesity and the recurrence of breast cancer, there is no evidence that losing weight will improve breast cancer outcomes. However, there is evidence that weight control contributes to good health, which makes it a worthwhile goal for everyone.

**I have heard that my chances of getting osteoporosis are increased after being treated for breast cancer. Is this true?**

Perhaps. All women are at risk of *osteoporosis* (a weakening of the bones). Women who experience early menopause because of chemotherapy are at increased risk of this condition. Although tamoxifen is not associated with osteoporosis, some other breast cancer drugs called aromatase inhibitors (such as anastrozole, letrozole and exemestane) may increase bone loss. If you have experienced early menopause or if you are taking an aromatase inhibitor, you should have a bone mineral density test to assess your bone health. This will help your doctor determine if you need treatment for osteoporosis.

**I am having difficulty with sex. Is there anything I can do?**

While you are receiving chemotherapy, you may feel less interested in sex, experience pain during intercourse or have trouble achieving orgasm. After you complete chemotherapy, you may experience fewer problems. Studies suggest that after treatment is finished, there is no difference in sexual problems between women treated for breast cancer and women not treated for breast cancer. In fact, some difficulties with sex may be related to menopause rather than to treatment. Talk to your doctor if you have any concerns.

**I would like to have a baby. Will this affect my cancer coming back?**

The answer to this question is not straightforward. At present, there is a lack of evidence that becoming pregnant can influence the chance of breast cancer recurring. Talk to your doctor if becoming pregnant is something you are thinking about.

## **Questions and answers on breast cancer**

### **Guideline 10: The management of persistent pain after breast cancer treatment**

#### **I've had breast cancer treatment, and now I'm having pain. Does this mean the cancer has come back?**

Pain after breast cancer surgery and treatment may occur for several reasons. In many cases, the pain may be caused by something that has nothing to do with breast cancer or its treatment. It may also be a result of the surgery, radiotherapy or chemotherapy you have experienced. Another possibility is that breast cancer has returned. If you have persistent pain at any time, you should consult your physician for assessment and advice. Additional investigations may be required. Regardless of the cause of pain, effective treatment is available.

#### **What types of pain may come from surgery?**

One cause of pain is the "postmastectomy syndrome." This occurs because removal of a lump can damage nerves in the area. This problem is more common after a total mastectomy (removal of the whole breast) but can also follow a lumpectomy (removal of just the cancer), especially if you have also had lymph nodes removed in the armpit area. Usually, this type of pain is not severe and will gradually improve.

Swelling of the arm (lymphedema) is another condition that can cause discomfort and pain. Removal of lymph nodes from the armpit during surgery can damage the channels that drain lymph from the arm. This leads to swelling and can be painful for some patients (see [guideline 11](#)).

#### **Could my pain be related to anticancer drugs?**

Some drugs may cause painful conditions, including bladder inflammation (cystitis), numbness and tingling (peripheral neuropathy), mouth ulcers (mucositis) and aching joints. Taking drugs intravenously may also cause painful inflammation of the veins (phlebitis).

### **What about pain caused by cancer?**

Cancer that grows in the bones may cause pain. If you have new or increasing pain in the bones, you should discuss this with your physician. These symptoms could occur because breast cancer has spread to the bones.

Although the bones are the most common site in which cancer returns, pain can also occur from cancer spreading to nerves and other organs.

One type of nerve pain is called “brachial plexopathy.” A burning or stabbing pain is felt in the arm, shoulder or hand when these areas are touched, or they may feel “different” — either numb or very sensitive. There may also be weakness in the arm, especially if the pain has been going on for a long time. Although this kind of pain may rarely be a side effect of radiotherapy or surgery, this pain may mean that cancer has come back in the lymph nodes behind the collarbone. Careful investigation may be necessary to rule out cancer.

### **Should medication get rid of all my pain?**

Regardless of the cause of pain, anti-pain medication prescribed by your physician can usually provide good pain control.

If the pain is caused by cancer, anticancer treatment such as radiotherapy or chemotherapy may treat the cause of the pain and reduce the need for pain medications.

It is important not to ignore pain or hope you will get used to it. People do not get used to pain. Putting up with pain can make it even harder to control later with medication. The goal of pain medication is to control pain as *rapidly* and *completely* as possible. This may require adjusting the type and amount of your pain medication. Remember, only you can report on your pain, and you need to let your doctors know if your pain is not controlled. If the pain is persistent or chronic, you will need to take pain medication in regular doses around the clock. Additional doses may be necessary in case of “breakthrough” pain between regular doses. If you often have breakthrough pain, your regular dosage may need to be adjusted or another medication prescribed.

### **What kind of medication should I be taking to get rid of the pain?**

If your pain is mild to moderate, painkillers you can buy without a prescription, such as

acetylsalicylic acid (ASA), acetaminophen and ibuprofen (part of the family of drugs called nonsteroidal anti-inflammatory drugs), may be effective alone. You can choose the brand you are most familiar with, or ask your doctor or pharmacist to recommend one.

Ibuprofen and ASA are effective pain relievers, but they can have side effects. They may aggravate asthma and cause stomach ulcers or kidney damage. If you have stomach problems, there are new medications in the nonsteroidal anti-inflammatory group (for example, Cox 2 inhibitors) that may reduce your chances of having side effects.

If drugs like ASA, acetaminophen and ibuprofen alone do not control the pain, do not take more than the recommended dose. Higher doses will not help the pain but will increase your risk of having side effects. If these medications alone are not effective, your doctor can prescribe stronger medications. Opiates are a strong pain reliever. Several types are available. Your physician can work with you to select an opiate that is most effective for you (for example, codeine or oxycodone). Opiates are often most effective when they are prescribed with drugs such as ibuprofen, acetaminophen or ASA.

Many types of pain may require strong opiates such as morphine, hydromorphone or fentanyl. Any of these drugs may be effective depending on the patient and the situation. Usually a short-acting opiate is prescribed on a regular schedule (for example, every 4 hours). The dose taken will be increased every day or so until pain is controlled.

Some patients find that taking pain medications frequently is difficult. If your pain is well controlled, then you can consider switching to a long-acting opiate, which some patients find more convenient. Several long-acting preparations are available. Long-acting tablets are taken twice a day, and a long-acting patch, which allows pain medicine to be absorbed through the skin, works for 3 days. You should discuss with your physician whether one of these approaches is right for you.

Occasionally, some patients will need to take opiates by injection under the skin instead of by mouth. As well, suppositories can be used in some patients. Your physician can advise you which is the best option depending on your situation.

### **If I take opioids, what side effects should I watch out for?**

All opioids can cause constipation. Laxatives should always be prescribed along with them.

You will need to take the prescribed laxatives regularly to prevent constipation.

Nausea and vomiting may occur when you start taking an opioid, but these symptoms often disappear completely after a short time. In the meantime, there are many drugs that can control these side effects, such as dimenhydrinate (Gravol). You can buy these drugs without a prescription under several brand names. Additional options to prevent or treat nausea are available by prescription.

Sedation (feeling sleepy) or confusion can be a problem, especially for elderly patients. No one should drive or use potentially dangerous equipment for 3 to 5 days after starting opioid therapy or after any change in dosage. The drowsy feeling usually disappears with time.

Although these are the most common side effects, individuals vary a great deal in their reactions to opioids. This means that a particular side effect may disappear entirely if you switch from one opioid drug to another. For example, if you have an unpleasant reaction to morphine, your doctor can try other opioids such as hydromorphone, oxycodone or fentanyl.

The effectiveness of your medication should be re-evaluated after 24 hours every time you switch from one opioid to another, change your dosage or change the way you take the drug (for example, if you switch from tablets to injections).

It is important to report side effects to your doctor. You should not stop taking opiates because of side effects without first discussing it with your doctor.

### **Won't I get addicted to morphine or some of these other drugs?**

True addiction (“psychological dependence”) is extremely rare when opioids are taken for cancer pain. Much more commonly, people who are not receiving enough medication may *seem* addicted simply because their continuing pain requires higher doses or switching to a stronger medication.

Rarely, you may develop “tolerance” to the pain medication. With tolerance, your body gradually becomes resistant to the medication and needs increasing amounts to get the same relief. Fear of developing tolerance is never a good reason to avoid taking enough pain medication to be pain free. Remember, there is no maximum dose for opioids, and the right amount to take is the amount that relieves your pain. If tolerance occurs, switching to another

type of pain medication will relieve the pain.

Anyone who takes an opioid for longer than a few weeks may become “physically dependent.” This means that your body gets used to the drug, and withdrawal symptoms will appear if it is suddenly stopped. When the cause of the pain improves and an opioid drug is no longer needed for pain, it should be reduced gradually over a couple of weeks.

### **Are there other drugs that can be used?**

Some drugs that are primarily used for other conditions have also proved useful in the relief of pain caused by cancer. These drugs are taken together with the pain medications already mentioned. Among these are corticosteroids, tricyclic antidepressants, anticonvulsants, some local anesthetics and bone-strengthening drugs called bisphosphonates.

In prescribing any of these drugs, your doctor should explain the possible side effects.

### **Are there other ways to help me deal with pain?**

There are various methods that may help, including exercise, electrical stimulation of nerves, acupuncture, massage, vibration and the application of heat or cold to the overlying skin. However, deep-heating methods such as diathermy and ultrasound should be used with caution, since they may help cancer cells to grow. Compression therapy may help control the swelling and discomfort caused by lymphedema.

There are also many alternative therapies such as meditation, biofeedback, prayer, visualization, yoga, Qi Gong, Tai Chi, therapeutic touch, Reiki, healing touch, homeopathy and herbal medicines. Although you should be aware that there is a lack of scientific evidence supporting these methods, there is also no proof that they do not work. In fact, many patients report significant benefit from their use. Remember, too, that pain always has a psychological element, and pain can be worse if you are depressed, tired or anxious. For this reason, you may find real benefit in joining a support group or trying psychological techniques such as hypnosis.

### **What if I have tried everything, including medication, without satisfactory pain relief?**

This kind of stubborn pain happens very rarely. If possible, you should see a pain specialist

who can use a variety of surgical measures to block the nerves involved.

# Questions and answers on the management of lymphedema related to breast cancer

## A guide for women and their physicians

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### What is lymphedema?

Lymphedema is the swelling that occurs when a protein-rich fluid called “lymph” collects in part of the body. In lymphedema related to breast cancer, this pooling of fluid usually occurs in the upper arm, where it can lead to pain, tightness and heaviness, and recurrent skin infections.

### What causes lymphedema?

Normally lymph flows through the lymphatic vessels and eventually enters the blood stream. Sometimes the flow of lymph is interrupted by damage to the vessels and the oval-shaped structures called “lymph nodes” that are located along the vessels.

In breast cancer patients, damage to the lymphatic pathways can be caused by the cancer itself, infection or certain breast cancer treatments. For instance, lymphedema can occur following removal of the lymph nodes in the armpit or “axilla” (called “axillary lymph node dissection”; see guideline 4 on the removal of lymph nodes during breast cancer surgery [www.cma.ca/cmaj/vol-158/issue-3/breastcpg/0022.htm]). Lymphedema can also occur when radiation therapy to the armpit causes scarring and blocks or slows the flow of lymph.

In many cases, lymphedema develops within the first year after surgery or radiation therapy, but it can develop at any time. It can be a temporary or a long-term problem.

### How is lymphedema measured?

If you or your doctor suspect that you have developed lymphedema after surgery or radiation therapy, you will need to be assessed. Your doctor may use a tape measure to compare the distance around each of your arms at different points and around your wrists and hands. A difference of 2 cm at any of these measurement points may require treatment. Your doctor will also check for tightness and feelings of heaviness in your arms. This assessment will allow your doctor to determine whether your lymphedema is mild, moderate or severe (severe lymphedema rarely occurs following breast cancer treatments). There are other methods of measuring lymphedema, such as water displacement, but they are used less often.

### My doctor says I have lymphedema. What are my treatment choices?

Before you begin treatment for lymphedema, you will want to make sure that you do not have any other problems related to your original breast cancer. Your doctor will check for infection in your arm and tumours in your armpit. Your doctor will also check for blood clots in your armpit (called “axillary vein thrombosis”). Once your doctor has ruled out these

problems, you can begin treatment for lymphedema.

Usually you will be offered treatment that involves wearing a compression garment. Other treatments, such as using a pneumatic compression pump or undergoing massage and physical therapies, are sometimes offered in addition to, or instead of, a compression garment. However, you should keep in mind that, at this time, the only treatment that can be recommended on the basis of scientific evidence — information from studies involving large numbers of women — is the use of a compression garment.

### *Compression garments*

A compression garment (sometimes called a “compression sleeve”) is a tight-fitting piece of elastic clothing that covers all or part of the arm. It may also cover the wrist or part of the shoulder. Good compression garments are usually custom-made. They should be replaced every 4 to 6 months or when they begin to lose their elasticity. Ideally, trained personnel should fit the garment for you.

A compression garment works by putting pressure on your swollen arm and stopping the collection of lymph in any one area. Your doctor may recommend that you wear the garment 24 hours a day or that you wear it only during waking hours. Whatever your doctor recommends, you should keep in mind that research shows that the long-term and consistent use of compression garments for lymphedema will result in improvement.

### *Pneumatic compression pumps*

A pneumatic compression pump is a device with a sleeve that can be inflated with compressed air in order to massage the arm. The device squeezes the lymph away from the hand and arm and toward the body. There are several commercially available pumps, ranging in complexity and cost. Most pumps used by therapists, clinics and patients are complex and cost several thousand dollars.

Unfortunately, no studies have been published regarding the most effective kind of pump, the most desirable pumping time or the best pressure levels. One thing that is known, though, is that you should not use pump therapy if you have an active infection or problems with blood clots (called “deep vein thrombosis”).

### *Massage and physical therapies*

Massage and physical therapies are used to help the fluid drain from the affected area. Manual lymph drainage is a massage technique that involves the skin surface only. The therapist tries to improve drainage from the arm by clearing out the main lymphatic pathways of the body, starting in the neck and moving to the main part of the body. Complex

physical therapy, also called complex decongestive physiotherapy, is a treatment routine that involves manual lymph drainage, skin care, bandaging, exercises and the use of compression garments.

In one study, the use of a compression garment combined with manual lymph drainage was compared with the use of a compression garment alone. Women in both groups had reduced arm volume and improvement in symptoms. However, manual lymph drainage did not provide additional benefit over the compression garment alone.

### Other therapies

There are other therapies for lymphedema that you may hear about: laser treatment, electrical stimulation, transcutaneous electrical nerve stimulation (TENS), cryotherapy, microwave therapy, thermal therapy, surgery, and drug therapy with diuretics or benzopyrones. There is no research that indicates whether these therapies are useful. These therapies require further study and are not recommended at this time.

### What should I do if I am having pain?

You must tell your doctor if you are having pain. Most often, the best way to control the pain is to control the lymphedema. You may need to change your treatment in some way. If changing your treatment does not help the pain, your doctor may prescribe an anti-pain medication (see guideline 10 on pain management [www.cma.ca/cmaj/vol-158/issue-3/breastcpg/0071.htm]).

### What can I do to help myself?

There are several things you can do to manage your lymphedema and prevent complications:

- *Look after your skin.* Avoid cuts, pinpricks, hangnails, insect bites, pet scratches and burns to the affected arm. If your skin is injured, be sure to clean and protect the wound immediately. Stay away from substances that you are allergic to or that you find irritate your skin. Whenever possible, avoid blood pressure monitoring in the affected

arm and avoid medical procedures that require pricking the skin in the affected arm (vaccination, blood drawing, insertion of an intravenous needle, acupuncture, and venography or lymphangiography [x-ray assessments that involve injections]).

- *Treat skin infections promptly.* Usually skin infections are streptococcal — that is, they are caused by bacteria called “streptococci.” On rare occasions an infection may be staphylococcal — caused by bacteria called “staphylococci.” In either case, the infection should be treated immediately with antibiotics such as penicillin. If you have recurrent infections, you may want to take regular preventive doses of antibiotics or receive monthly injections of penicillin. Your doctor may want you to have an emergency home supply of an antibiotic, to be taken at the first sign of infection. If you are visiting a remote area, be sure to take along a supply of antibiotics.
- *Use saunas, steam baths and hot tubs with care.* Heat can make your lymphedema worse. Be cautious about exposing yourself to hot environments.
- *Travel with care.* Some patients report that their lymphedema is worse when they travel to places with a hot climate. Some also report that their lymphedema is worse during flights. If you have a compression garment, you should wear it when travelling by air.
- *Exercise your arms.* Activities that exercise your arms may help control your lymphedema. Although some doctors say you should avoid activities such as rowing, tennis, golf, skiing, squash and racquetball, there is no research to suggest that these sports promote or worsen lymphedema. In fact, in one study, 20 women with breast cancer competed in the strenuous sport of dragon boat racing and found that the activity did not promote or worsen lymphedema. Some experts recommend that you wear a compression garment during exercise.
- *Maintain an ideal body weight.* Being overweight can contribute to the development of lymphedema and may make the use of compression garments or pneumatic compression pumps less effective.

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## Appendix 2

# Questions and answers on chemoprevention and breast cancer

## A guide for women and their physicians

### Is this guide for me?

This guide is for women who have never had breast cancer and are thinking about taking a drug called tamoxifen to prevent breast cancer. If you are concerned about your risk of getting breast cancer, you may want to read on. Note that this guide is about taking tamoxifen to prevent breast cancer — it does *not* cover other ways to prevent breast cancer.

### What is chemoprevention?

Chemoprevention refers to the use of medications to reduce a person's chance of developing cancer. You and your doctor may want to discuss chemoprevention if your risk of breast cancer is higher than the risk of other women your age.

Estrogen plays an important role in the development of breast cancer. Drugs that can block the action of estrogen have been studied to see if they can prevent breast cancer. Two of these drugs are tamoxifen and raloxifene.

### What is tamoxifen?

Tamoxifen can affect the growth of cancer cells by blocking estrogen. The use of tamoxifen to prevent breast cancer has developed from its use to treat women with breast cancer. Research has shown that women with early breast cancer who take tamoxifen as part of their cancer treatment have a reduced risk of recurrent breast cancer. Studies have also shown that women with breast cancer treated with tamoxifen have a reduced risk of cancer in the opposite breast.

### What have researchers learned about tamoxifen?

Three studies have examined tamoxifen for breast cancer prevention: the National Surgical Adjuvant Breast and Bowel Project P-1 (NSABP P-1) Study, which took place in Canada and the United States, the Italian Tamoxifen Prevention Study and the Royal Marsden Hospital Trial, which took place in the United Kingdom. All of the studies compared women taking tamoxifen and women taking an inactive drug called a "placebo."

Women with a higher risk of breast cancer who took tamoxifen in the largest trial (the NSABP P-1 study) had a significant reduction in breast cancer events (about 50%). However, women in the 2 smaller trials (Italian and Royal Marsden) did not. At this time we do not know if taking tamoxifen will increase a woman's chance of living longer.

Women taking tamoxifen were more likely than those taking a placebo to experience problems with stroke and blood clots in the lung or leg veins. In the NSABP P-1 study, there was an increase in cases of uterine cancer among women taking tamoxifen.

### What are the benefits and risks of using tamoxifen for chemoprevention?

Tamoxifen can reduce the chance of breast cancer developing

in women at higher risk of the disease. It can also cause harmful side effects. Side effects associated with the use of tamoxifen include stroke, blood clots in the lung or leg veins, cancer of the uterus, hot flashes and vaginal dryness. Obviously some of these effects are more serious than others.

In general, the likelihood of some of the side effects increases with a woman's age. The benefit of protection against breast cancer is more likely to outweigh the risks in women aged 35 to 50. As age increases, the risk of side effects (especially stroke and blood clots in the lung) will increase, and at some point outweigh, the potential benefits of taking tamoxifen.

### How do I find out about my risk of breast cancer?

"Risk" is the likelihood that a particular disease will develop in a particular person during a particular time. Determining risk is not easy. Your doctor will assess your risk of breast cancer by looking at a number of factors, including the following:

- Your age
- When you had your first menstrual period
- When you had your first child
- Whether you have had a biopsy for breast cancer
- Whether you have a close relative (mother, sister or daughter) with breast cancer
- Your ethnic origin

### What is the Gail risk assessment index?

The Gail risk assessment index is a model used to estimate an individual woman's risk of breast cancer. The index uses a series of risk factors (age, age at first period, age at first live birth, number of breast biopsies, family history and ethnic origin) to calculate a "baseline risk." This is a woman's chance of invasive breast cancer developing over the next 5 years and over her lifetime.

For example, if your baseline risk of breast cancer is estimated to be 2%, during a 5-year period you have a 2% chance of breast cancer developing (and a 98% chance of the disease *not* developing). Another way to think about this is that, in the next 5 years, breast cancer would develop in 2 out of 100 women like yourself, and it would not develop in 98. Your individual risk is then compared with the risk of women the same age considered to be at *average* risk of breast cancer. For example, although your risk of breast cancer might be 2%, the risk of women in your age group with average risk factors might be 1%.

If you and your doctor are concerned that you may be at increased risk of breast cancer, the risk assessment index can help you begin thinking and talking about chemoprevention (see the Breast Cancer Risk Assessment Tool at <http://bcra.nci.nih.gov/brc>).

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**Should the Gail risk assessment index be used routinely to make treatment decisions?**

No, a family physician should not use the Gail index on every woman. Although this index was used for enrolling women in the NSABP P-1 study (the one study that showed a potential benefit of tamoxifen use in preventing breast cancer), it has not yet been evaluated for routine use in your physician's office. In addition, you should know that the Gail index was developed using information from a large number of white women and a very small number of non-white women; it is unknown whether this model can be used with the same degree of accuracy in women of all ethnic origins. However, when a woman or her physician are concerned about her increased risk of breast cancer, the index can be useful in deciding whether to further discuss the benefits and harms of taking tamoxifen.

**What information will I need to decide about using tamoxifen to prevent breast cancer?**

First, you will need to know more about your risk of developing breast cancer during the next 5 years. You and your doctor or a specialist at a counselling centre might use the Gail index to estimate your risk. You will then need to consider evidence from the NSABP P-1 trial, in which women with a baseline risk of at least 1.66% at 5 years, according to the Gail index, participated. Results from the study suggest that taking tamoxifen will reduce your risk. Next you will have to learn more about the possible benefits of taking tamoxifen and the possible harms of side effects.

**I am at low or normal risk of breast cancer (less than 1.66% at 5 years, according to the Gail index). Should I consider chemoprevention?**

No. Researchers and physicians do not recommend chemoprevention for women at low or normal risk of breast cancer because the potential for harm outweighs the possible benefit of tamoxifen therapy.

**I am at higher risk for breast cancer (1.66% or greater at 5 years, according to the Gail index). Should I consider chemoprevention with tamoxifen?**

Yes, but you will need to discuss the possible effects of tamoxifen with your doctor and perhaps with a specialist at a counselling centre. You will want to consider how you might be affected by breast cancer versus how you might be affected by a stroke or blood clots in the lung. You will also want to consider quality-of-life issues such as tamoxifen-associated hot flashes and vaginal dryness. You will need to weigh the potential benefits of chemoprevention against the potential harms of side effects. The value you place on the different possible outcomes will influence your choice. For example, you might feel that a tamoxifen-induced stroke would be far worse than breast cancer and decide against taking tamoxifen. Another woman might feel that breast cancer would be far worse than a stroke and decide to take tamoxifen. You will have to determine the value you place on the possible consequences of taking or not taking tamoxifen after a full discussion with your doctor. If you decide to take tamoxifen, it is recommended that you take it for 5 years.

**Should I consider chemoprevention with the drug raloxifene?**

Raloxifene, like tamoxifen, can block estrogen and affect the growth of cancer cells. It was originally studied in women with osteoporosis — a common cause of brittle bones and fractures in postmenopausal women. One study has suggested that raloxifene reduces the risk of the development of breast cancer. Although raloxifene research is promising, a study designed specifically to evaluate its use for the prevention of breast cancer has not been completed yet. A trial that will compare raloxifene and tamoxifen for breast cancer prevention (NSABP STAR trial) is underway. Researchers hope it will answer some of the many questions about the effects of raloxifene. Current evidence does not support the use of raloxifene for chemoprevention of breast cancer outside of a clinical trial.

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## Appendix 1

# Questions and answers on sentinel lymph node biopsy

## A guide for women and their physicians

### I am about to begin treatment for breast cancer. What surgical procedures are used to find out if cancer has spread to my lymph nodes?

The most commonly used method for determining the extent or “stage” of a breast cancer is “axillary dissection” — a surgical procedure that involves removing and examining lymph nodes (sometimes called “glands”) from the armpit (see guideline 4 on the removal of lymph nodes during breast cancer surgery [www.cma.ca/cmaj/vol-158/issue-3/breastcpg/0022.htm]).

“Sentinel lymph node biopsy” is an alternative staging method. It is a newer surgical procedure that involves removal and examination of 1 or 2 lymph nodes identified as the most important in the area where the cancer was found.

### Why are lymph nodes removed?

Lymph nodes are part of the system that carries a fluid called “lymph” around the body. When breast cancer spreads, cancer cells often collect in the lymph nodes in the armpit. By removing some of the lymph nodes in the armpit and examining them under a microscope, doctors can obtain important information about how far the cancer has progressed. Information on whether the nodes are “positive” (contain cancer cells) or “negative” (do not contain cancer cells) will help determine the right treatment for you after surgery (see guideline 7 [www.cma.ca/cmaj/vol-164/issue-2/breastcpg/guideline7rev.htm] and guideline 8 [www.cma.ca/cmaj/vol-164/issue-5/breastcpg/guideline8rev.htm]). Removal of lymph nodes also reduces the risk that cancer will come back in the armpit area.

### What is sentinel lymph node biopsy?

During a sentinel lymph node biopsy, radioactive material or a dye, or both, is injected into the breast tissue surrounding the tumour or the place where the tumour was removed. As the lymph carries the material or dye through the lymphatic pathways, the surgeon uses a device to identify the first node the lymph reaches (the “sentinel lymph node”), which is then removed by the surgeon for examination in the laboratory by a pathologist.

If the sentinel lymph node is found to be positive (to contain cancer cells), this suggests that other nodes in the area may be positive. If the sentinel lymph node is found to be negative (not to contain cancer cells) this suggests that other nodes in the area are also negative. Thus, the sentinel lymph node is thought to accurately reflect the state of all the nodes in the armpit.

### What are the benefits of sentinel lymph node biopsy?

If you have sentinel lymph node biopsy you may avoid some of the side effects related to axillary dissection. These side effects include restriction of shoulder movement, pain, numbness and lymphedema (arm swelling) (see guideline 4

[www.cma.ca/cmaj/vol-158/issue-3/breastcpg/0022.htm] and guideline 11 [www.cma.ca/cmaj/vol-164/issue-2/0191.htm]).

### What are the disadvantages of sentinel lymph node biopsy?

When a sentinel lymph node biopsy is performed, there is a small chance, usually less than 10%, that even though no cancer cells are found in the sentinel lymph node, cancer cells are present in other lymph nodes in the armpit. You should be aware that missing these cancer cells may affect the treatment you receive after surgery and the chance of breast cancer returning.

### What should be done if the sentinel lymph node is negative for cancer?

If the sentinel lymph node is found to be negative, further surgical procedures are not required for staging the cancer.

### What should be done if the sentinel lymph node is positive for cancer?

If the sentinel lymph node is found to be positive, this suggests that other lymph nodes in the armpit may contain cancer cells and an axillary dissection should be done.

### What are some of the questions you should ask your surgeon about sentinel lymph node biopsy?

Sentinel lymph node biopsy is a challenging procedure to perform and is only mastered with experience. This means that medical specialists who have not performed a large number of these biopsies may have a high failure rate; that is, they will not be able to accurately and consistently identify the sentinel lymph node and determine whether it does or does not contain cancer cells. You should ask your surgeon the following questions:

- *How often do you perform breast cancer surgery? A surgeon who does not perform breast cancer surgery frequently should not do sentinel lymph node biopsy.*
- *How many sentinel lymph node biopsies have you performed, and what is your success rate with the procedure? Surgeons offering to perform this procedure should inform patients of the number of biopsies they have completed and the number of times they have correctly identified the sentinel lymph node. They should indicate the number of times they have found cancer cells in the lymph nodes in the armpit when the sentinel lymph node was negative.*

When surgeons first start performing sentinel lymph node biopsy, they should also perform back-up axillary dissection on all patients. It has been suggested that, before a surgeon

performs sentinel lymph node biopsy alone (without axillary dissection), he or she should have performed at least 30 sentinel lymph node biopsies followed by axillary dissection. In these 30 cases, the surgeon should have identified the sentinel lymph node at least 85% of the time and found cancer cells in the nodes under the arm in no more than 5% of cases when the sentinel lymph node was negative.

### When should sentinel lymph node biopsy *not* be performed?

If you have had breast surgery or radiation to the breast in the past, you should not have sentinel lymph node biopsy. You should also not have the biopsy procedure if you have "clinically palpable nodes" (lymph nodes that your doctor can

feel), "locally advanced breast disease" (very extensive cancer in the breast) or tumours in more than one location in the breast, or if you have had breast reduction surgery in the past.

### Should I have sentinel lymph node biopsy instead of axillary dissection?

You will need to discuss this question with your doctor and the other medical specialists involved in your care. Axillary dissection is still the most widely accepted treatment for the surgical staging of breast cancer. You and your doctor will need to discuss what is and is not known about sentinel lymph node biopsy before you make a decision about which procedure is best for you. You may choose to participate in a clinical research trial of sentinel lymph node biopsy.

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## Appendix 1

# Questions and answers on the use of hormone replacement therapy (HRT) by women who have had breast cancer

## A guide for women and their physicians

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### What is hormone replacement therapy?

Hormone replacement therapy (HRT) refers to treatment with pills or skin patches that contain the hormone estrogen or the hormones estrogen and progesterone combined. Hormones are chemicals that affect the activity of certain cells or organs. For example, both estrogen and progesterone play an important role in a woman's life, regulating menstrual periods and affecting the growth of breast tissue. These hormones are produced in the ovaries, but they can also be made in a laboratory or obtained from plants and animals.

### Why is HRT prescribed?

As women leave their child-bearing years behind, they begin to produce less estrogen and progesterone. Lack of estrogen can lead to unpleasant menopausal symptoms such as hot flashes and vaginal dryness. A lack of estrogen can also contribute to osteoporosis (the loss of bone tissue). HRT is often prescribed to relieve menopausal symptoms and reduce the risk of osteoporosis. HRT may also be prescribed when a woman experiences premature menopause, whether naturally or as the result of medical treatment.

### I have been treated for breast cancer in the past. I am now having hot flashes and other menopausal symptoms. Should I take HRT?

Probably not. At present, too few studies of HRT use by women with breast cancer have been completed. In addition, the study results available do not indicate whether HRT is safe for women who have had breast cancer.

### Why is HRT considered unsafe for women who have had breast cancer?

Researchers know that estrogen plays a role in the development of breast cancer. Studies using animals have shown that estrogen affects breast cancer growth. Other kinds of studies have shown that women exposed to more estrogen throughout life — for example, women who begin their periods at an early age or enter menopause at a late age — are at increased risk of breast cancer. Studies have also shown that women who have never had breast cancer increase their risk of the disease if they take HRT for an extended period. The risk of breast cancer increases for each year of use. A woman who has had breast cancer is at risk of having the cancer return or of developing another cancer in the opposite breast. This knowledge, combined with research findings about estrogen, has led to a concern that HRT could trigger the recurrence of breast cancer in a woman who has already had the disease.

### Are there alternatives to HRT?

Yes. Several alternative treatments have been studied and found to relieve menopausal symptoms:

- *Hot flashes:* Venlafaxine, a relatively new antidepressant medication marketed as Effexor.
- *Vaginal dryness:* K Y lubricating jelly and Replens, a vaginal moisturizer.
- *Sexual and urinary problems:* Estradiol vaginal rings such as Estring, which provide controlled local delivery of very low doses of estrogen. (Creams are not recommended because the estrogen in them passes into the blood, and this can lead to high concentrations of estrogen in the body.)

Other alternative treatments have been found to improve bone mass and reduce the risk of osteoporosis:

- Exercise, a diet rich in calcium, and appropriate mineral and vitamin supplements.
- Bone-strengthening drugs called bisphosphonates.

One drug used to treat osteoporosis that is not recommended for women who have had breast cancer is raloxifene, a selective estrogen receptor modulator. Although it is similar to tamoxifen, a drug commonly used in the treatment of breast cancer, there are no studies supporting raloxifene's use in women with breast cancer.

### Are there other alternatives not mentioned here?

Yes. There are alternative treatments not mentioned here, including various hormone preparations, herbs and vitamins. Some of these therapies for menopausal symptoms have been studied and found to be ineffective or potentially harmful, while others have not been studied enough and cannot be recommended yet.

### What can I do if alternatives to HRT do not help?

If your menopausal symptoms are particularly troublesome and they are not relieved by any of the alternative approaches listed here, you might want to discuss HRT with your doctor. You will need to talk about many things, including when you had cancer, what kind of cancer you had and how your cancer was treated. You will need to weigh the risk of having your breast cancer return or of developing another cancer in the opposite breast against your present discomfort. If you decide to use HRT, your doctor will probably suggest a low dose and a short treatment period.

## Appendix 1

# Questions and answers on the treatment of locally advanced breast cancer

## A guide for women and their physicians

### What is locally advanced breast cancer?

Patients with *locally advanced breast cancer* or *LABC* have large breast tumours (more than 5 cm wide) and one or more of the following:

- Tumours that are attached to the chest wall or skin, or skin that is ulcerated or red.
- Lymph nodes (sometimes called *glands*) in the armpit that have become attached to structures in the armpit.
- Lymph nodes above the collarbone (called *supraclavicular nodes*) that contain cancer cells.

These features indicate that the cancer is more extensive than earlier stage breast cancer (see guideline 3) but has not yet spread or *metastasized* to other parts of the body. Inflammatory breast cancer, which makes the breast red and swollen, is a type of LABC.

### How is LABC treated?

The treatment of LABC is complex and must be tailored to the individual. Patients will often need a combination of therapies (called *combined modality treatment*), which includes:

- Chemotherapy (treatment with anticancer drugs)
- Radiotherapy (treatment with high-energy x-rays)
- A mastectomy (surgery that removes all breast tissue)
- Hormonal therapy (treatment with the drug tamoxifen)

Usually 3 cancer specialists — a surgeon, a medical oncologist and a radiation oncologist — will work together to choose and schedule the best combined modality treatment for you.

### What more can I learn about LABC from this guide?

This guide summarizes a list of recommendations for treating patients with LABC. The recommendations have been written with the use of a treatment framework based on whether or not surgery is possible for the patient with newly diagnosed LABC. In other words, is the tumour *operable* (it can be removed completely in an operation) or is it *inoperable* (it cannot be removed completely)?

Inoperable tumours are either:

- attached to the chest wall or skin, or
- inflammatory, or
- have lymph nodes attached to structures in the armpit, or have spread to a lymph node above the collarbone.

### I have an operable tumour...

#### *Will I be offered chemotherapy?*

Yes, you will probably be offered chemotherapy unless your general health indicates that you would not tolerate it well. In general, the chemotherapy should include anthracyclines (anticancer agents such as doxorubicin and epirubicin). You will most likely have 6 months of chemotherapy (see guideline 8) — scheduled in 1 of 2 ways:

- Anticancer drugs will be given before surgery to shrink the tumour and make surgery easier, or
- Surgery will be done first and then anticancer drugs will be given to try to destroy any remaining cancer cells.

You will need to discuss with your doctor which approach will be

used. You will also need to see if your health and level of fitness allow you to have chemotherapy.

#### *Will I be offered radiotherapy?*

Yes, you will probably be offered radiotherapy. This is usually scheduled after surgery and chemotherapy. The radiation will be directed at your chest wall and at the lymph nodes in your armpit and above your collarbone.

#### *Will I be offered hormonal therapy?*

Yes, if you have a tumour that is identified as one that is likely to respond to hormones. In that case, your doctor will probably recommend that you take tamoxifen (a drug that blocks the effect of estrogens) for 5 years after you finish the chemotherapy and radiotherapy, to decrease the chance of the cancer returning. Women who may not tolerate chemotherapy may be offered tamoxifen instead.

### I have an inoperable tumour...

#### *Will I be offered chemotherapy?*

Yes, you will probably be offered chemotherapy that includes anthracyclines (anticancer agents such as doxorubicin and epirubicin). If anthracycline-based chemotherapy does not help, you may then be offered taxane-based chemotherapy (anticancer agents such as paclitaxel and docetaxel). If your cancer responds well to a particular kind of chemotherapy, you will have 4 to 6 months of treatment (see guideline 8). The way your cancer responds to the anticancer drugs will determine what treatment you receive next. For example, if the anticancer drugs make the tumour disappear, you may be offered surgery before radiotherapy. If the anticancer drugs have less effect, your physician will probably suggest radiotherapy before considering surgery. Your medical specialists will also need to consider other treatment options if your health and level of fitness do not allow you to have chemotherapy.

#### *Will I be offered radiotherapy?*

Yes, you will probably be offered radiotherapy. If your cancer responds to chemotherapy, you may be offered surgery with radiotherapy to follow. If your cancer responds less well to chemotherapy or you are not able to have chemotherapy, you will probably be offered radiotherapy first. At whatever point you receive radiotherapy, the radiation will be directed at your chest wall and at the lymph nodes in your armpit and above your collarbone.

#### *Will I be offered hormonal therapy?*

Yes, if you have a tumour that is identified as one that is likely to respond to hormones. In that case, your doctor will probably recommend that you take tamoxifen (a drug that blocks the effect of estrogens) for 5 years after you finish the chemotherapy and radiotherapy, to decrease the chance of the cancer returning. Women who may not tolerate chemotherapy may be offered tamoxifen instead.

# Questions and answers on radiotherapy after mastectomy

## A guide for women and their physicians

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### What is mastectomy?

*Mastectomy* is an operation that removes the whole breast. This is the type of surgery that you have undergone.

### What is radiotherapy?

*Radiotherapy* or *radiation therapy* is the use of high-energy x-rays to kill cancer cells. Depending on several factors, including where cancer cells have been found in the region of your breast, your medical specialists may recommend this treatment.

### What is post-mastectomy radiotherapy?

*Post-mastectomy radiotherapy* or *PMRT* is the term used for radiation applied, after mastectomy, to the locoregional areas (i.e., chest wall, armpit region and lymph nodes above your collarbone). The aim of this treatment is to stop the cancer from returning to these regions. Doctors refer to the reappearance of cancer in these regions as *locoregional recurrence*.

### Will I be offered PMRT?

Before deciding whether to offer you PMRT, your medical specialists will need to consider the risk of locoregional recurrence and whether PMRT is likely to prevent it. Studies have found that PMRT helps women who have cancer in 4 or more lymph nodes in the armpit. It is unclear, though, whether PMRT helps women who have cancer in only 1 to 3 lymph nodes in the armpit. Researchers are also looking at other factors, including the number of nodes removed from the armpit during surgery and the presence of cancer cells in the tissue near the surgical incision, to see if these factors will help to predict when PMRT should be offered; however, they have not reached a conclusion. PMRT is also often used when the tumour is large (for example, greater than 5 cm in diameter) or when the tumour invades the skin or chest wall.

### Will I be offered other treatment in addition to PMRT?

You may also be offered treatment with anticancer drugs (chemotherapy or hormonal therapy, or both). For more information about chemotherapy and hormonal therapy see guideline 8 (available at [www.cmaj.ca/cgi/content/full/158/3/DC1](http://www.cmaj.ca/cgi/content/full/158/3/DC1)).

### Is there a “best” treatment schedule for PMRT and chemotherapy?

There are 3 options for scheduling:

- *Sequential treatment*: chemotherapy first followed by radiotherapy, or radiotherapy first followed by chemotherapy.
- *Concurrent treatment*: chemotherapy and radiotherapy given at the same time.
- *“Sandwich” treatment*: chemotherapy given before and again after radiotherapy.

We do not have enough information yet to say whether one of these options is better than another. In many centres, PMRT is administered after chemotherapy. However, we do know that concurrent scheduling with chemotherapy based on anthracyclines (anticancer agents such as doxorubicin and epirubicin) or taxanes (anticancer agents such as paclitaxel and docetaxel) can lead to more side effects. For this reason, concurrent radiotherapy and chemotherapy using these anticancer drugs is not recommended.

### What are the possible side effects of PMRT?

PMRT commonly causes some mild, short-term side effects, such as tiredness and reddening of the skin. In rare cases, PMRT can also cause more serious, long-term side effects. These include lymphedema (swelling of the arm), pneumonitis (inflammation of lung tissue), cardiac injury (heart problems), brachial plexopathy (nerve problems in the arm, chest and shoulder), broken ribs and new cancers elsewhere in the body.

## Where can I find support?

It has long been known that patients who have a good network of social and emotional support feel better. There is now some evidence that this kind of support can not only help control problems like pain, nausea and depression but may even prolong life in the long term after breast cancer has been diagnosed.

Good support is part of good cancer care. It can take many forms, including regular visits to a health professional, interaction with other women who have had breast cancer or simply talking things over

with a relative or a good friend. Any or all of these can make a great deal of difference.

Ask your doctor about breast cancer support groups and advocacy groups in your area. The people in these groups know what you're going through and know how to help in a way no one else can. You can also call your local branch of the Canadian Cancer Society or the Cancer Information Service, toll-free at 888 939-3333. The family counselling or social work department at your regional cancer centre will also be able to help you find support groups.

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## CLINICAL TRIALS

## What is a clinical trial? My doctor has mentioned that I could participate in one.

A clinical trial is a carefully designed research study that usually involves comparing one cancer treatment with another. At some time you may be invited to take part in such a trial.

Whether you join the trial is entirely up to you. Just about everything that we already know about breast cancer treat-

ment comes from previous clinical trials. Yet, many questions about breast cancer treatment are still unanswered. Since there is still so much left to learn, new trials are urgently needed to plan the best care for the future. If you wish to add to knowledge in this way, ask your doctor about possible trials you could join.

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## INFORMATION

### Where can I find more information?

There are several places that can help you get the information and support you need. For example, you can call the nationwide the Cancer Information Service at 888 939-3333. There are no long-distance charges.

Many recent publications can help you learn more about your treatment and about coping with breast cancer. Some of the best include the following:

*Breast Cancer and You* by T.A. Al-Tweigeri, R. Clark, C. Harkness, R. Hasselback, J. Gorski, H. Hatton H and others. Published in *Current Oncology* 1996;S1-S32. Available without charge from the Cancer Information Service (tel 888 939-3333) or the National Breast Cancer Fund (tel 416 544-8487). A French version is available under the title *Vous et le cancer du sein*.

*The Complete Breast Book* by J. Engel. Published by Key Porter Books, Toronto. 1996 [ISBN 1-55013-643-7, 235 pages, paperback].

*Dr. Susan Love's Breast Book*. by S.M. Love and K. Lindsay. 2nd edition. Published by Addison-Wesley Publishing, Reading, Mass. 1995 [ISBN 0-202-40835-X, 627 pages].

*Everyone's Guide to Cancer Therapy: How Cancer Is Diagnosed, Treated, and Managed Day to Day* by M. Dollinger, E.H. Rosenbaum and G. Cable. 2nd revised edition. Adapted by the Canadian Medical Association. Published by Somerville House Books Ltd. Toronto. 1995. [ISBN 1-895897-40-8. 706 pages, paperback].

*Facts on Breast Cancer*. Canadian Cancer Society, Toronto. Available from the

Canadian Cancer Society (tel 416 777-4428). [booklet. 20 pages (Canadian Cancer Society code no. 211962)]. A French version is available under the title *Faits sur le cancer du sein*.

*Guide du traitement de la douleur chez le patient cancéreux*. (1995). Published by the Conseil consultatif de pharmacologie, Gouvernement du Québec. Bibliothèque nationale du Québec, 1995.

*Intelligent Patient Guide to Breast Cancer* by I. Olivotto, K. Gelmon and U. Kuusk. Published by Intelligent Patient Guide Ltd., 517-750 West Broadway, Vancouver BC V5Z 1H4, 1995 [ISBN 0-9696125-1-6. 280 pages].

*Pain Relief: Information for People with Cancer and their Families*. Canadian Cancer Society and Health Canada. 3rd revised edition. 1997. Available from the local office of the Canadian Cancer Society or the Cancer Information Service 888 939-3333. [booklet. 25 pages (Canadian Cancer Society code no. 311-578)]. A French version is available under the title *Soulager la douleur — Guide destiné aux personnes souffrant du cancer et a leurs familles*.

*What You Need to Know About Breast Cancer*. Published by The Burlington Breast Cancer Support Services Working Group, in collaboration with the Ontario Breast Cancer Information Exchange Network and Avon. 1996. Available from Avon (tel 800 265-2866). A French version is available under the title *Ce que vous devez savoir sur le cancer du sein*.♦